

State Title V Block Grant Narrative

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Sections 5.4 - 5.7, containing standard forms and detailed descriptions of national and State performance and outcome measures, are not included in this PDF. Data from these sections can be viewed in interactive formats on the Title V Information System Web site (http://www.mchdata.net).

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1.4 Overview of the State

South Carolina is a small and poor state with many of the problems associated with low socio-economic status. Almost 25 percent of the children in the state are in families whose income is below the poverty level. Nearly a third of South Carolina's children are in single parent families. The standardized test scores of South Carolina students rank among the worst in the nation. South Carolina scores very poorly on many indicators of maternal and child health status. The 1998 infant mortality rate stayed the same from 1997, which had increased from 1996. This recent trend has reversed a steady decline over the last twenty years. Over nine (9) percent of the babies in the state are low birthweight. Half of all births in South Carolina result from pregnancies that were unintended. About 40 percent of all pregnant women do not get early and continuous prenatal care. Death and disability due to motor vehicle crashes in children and youth, already above the national rate, are not going down. The gap between Black (and other races) and White populations for many health indicators is not improving.

By the Kids Count family risk index, 19 percent of the children in South Carolina are considered to be "high risk", having at least four of the following characteristics:

- C Child not living with two parents
- C Household head is a high school drop out
- C Family income is below the poverty line
- Child is living with parent(s) who do not have steady, full-time employment
- C Family is receiving welfare benefits
- Child does not have health insurance

A disproportionate share of the children in the Black (and other races) and the growing Hispanic populations are at high risk.

Although South Carolina ranks well in some indicators measuring economic growth and development, sharp disparities are evident. Unemployment rates are considerably higher in rural counties than in areas with a diversified industrial base. Employment may be readily available in areas where tourism is a major industry, but the jobs are more likely to be low wage and not offer health insurance benefits. Rural areas are more likely to be medically underserved. Functionally illiterate young families may not access programs designed to benefit them because paperwork and processes are too complex.

Throughout State Fiscal Year (SFY) 1999 (July 1, 1998-June 30, 1999) change and transition in several areas were striking and ongoing. The election of a new governor in November 1998 resulted in new agency heads for the Department of Health and Human Services (Medicaid agency) and the Department of Social Services, two of the Department of Health and Environmental Control's (DHEC-the Title V agency) primary partners in providing health services. The governor's signature legislation in the 1999 General Assembly, First Steps for School Readiness, was passed. This initiative, targeting the birth to age six population, offers an opportunity to improve the health and well

being of South Carolina's young children and families. Six health specific areas were identified in the legislation: nutrition; affordable access to quality age appropriate health care; early and periodic screenings; required immunizations; initiatives to reduce injuries to infants and toddlers; and technical assistance and consultation for parents and child care providers on health and safety issues. During the same legislative session, a law significantly increasing Medicaid reimbursement for dental services also passed. These two initiatives have the potential to greatly affect health care service delivery to children in coming years.

South Carolina's SCHIP program, "Partners for Healthy Children" (a Medicaid expansion), increased enrollment for children and also expanded eligibility during FY 1999. A diligent and concentrated outreach campaign by service providers, a simpler application process, and an emphasis on insurance instead of welfare greatly increased the number of children enrolled in Medicaid. The initial target to enroll 75,000 more children in the Medicaid program was greatly exceeded. As a result of the extensive outreach, in which DHEC played a large role, over 100,000 more children were enrolled and the Medicaid program in South Carolina now serves over 350,000 children birth through age 18. This enrollment effort is a success story and has received national recognition. The Medicaid program also received legislative approval to expand Medicaid eligibility for children, birth through age 18, to 165% of the poverty level. However, this expansion was not implemented because of financial deficits in the Medicaid agency.

Increased Medicaid reimbursement has provided an incentive for more physicians to accept more Medicaid patients for prenatal care and child care. Medicaid covers half of all births in the state. However, the distribution of Medicaid patients (the demand side) compared to overall physician distribution (the supply side) is still disproportionate. Rural areas in particular are chronically underserved.

How South Carolina communities view health and health care is in transition. More communities are looking at health care systems in a comprehensive manner. The Healthy Communities, Turning Point (a public health infrastructure community and state level planning process) and other holistic community assessment initiatives are active in over half of the counties in the state. DHEC supports this movement through leadership in county and community coalitions. DHEC districts (public health regions comprising from two to six counties) are encouraged to support and develop public/private partnerships, strengthen infrastructure building, and transition staff to provide more family support services (nursing, health education, nutrition, social services and paraprofessional services) and provide less direct primary care. The community role of health departments is changing toward more involvement in building, supporting and facilitating community health care systems through core public health assessment, assurance and policy development functions.

Within the DHEC Health Services area, transition and change continues. The number of community public/private partnerships for medical homes for children, including children with special health care needs, increased during SFY 1999. The DHEC role in these partnerships is to provide family support services, including nursing, health education, nutrition, social services and paraprofessional services. The number of DHEC nurses placed in public schools increased.

Planning started for DHEC to be a major partner in the First Steps for School Readiness program at both state and county levels. However, without the funding available through Medicaid reimbursement for direct services, districts are struggling to transition to more enabling and population-based services and infrastructure building. At the same time, county health departments are providing services for many families who have no health insurance. Even though Medicaid eligibility expansion has helped many families increase their access to care, a growing number of working poor families often have too much income for Medicaid eligibility, but receive no health insurance through their employer.

Several long term health systems problems continued during SFY 1999 with no change or improvement: low Medicaid reimbursement rates for subspecialty physicians, critical for services for children with special health care needs (CSHCN); insufficient or inadequate transportation for patients and families; and pressure from some hospitals to weaken the state perinatal regional system.

Title V provided invaluable guidance as well as funding during the changes and transition that occurred in South Carolina in SFY 1999. The MCH Pyramid of Health Services offers a concept and framework for building stronger health care delivery systems. Title V funding is the foundation for maternal and child health programs in South Carolina. Development of a web of inter-connecting health care delivery systems at local, district and state levels to improve the health status of women, children, youth and families, including families with children with special health care needs, is an ongoing, continuous process toward an ideal goal. Title V funding enabled the infrastructure building to take place for a MCH Pyramid of Health Services especially designed for this state. In summary, progress was made during SFY 1999 toward attaining our ideal health services system.

1.5 The State Title V Agency

1.5.1 State Agency Capacity

1.5.1.1 Organizational Structure

Resources, Statutory Authority and Structure:

The State Board of Health was established by the Legislature in 1878. The South Carolina Department of Health and Environmental Control (DHEC) was formed in 1973, when the Board of Health merged with the Pollution Control Authority. Statutory Authority for the department is primarily provided in Titles 44 and 48 of the South Carolina Code, 1976. The Department operates under the supervision of the Board of Health and Environmental Control, which has seven members, one from each Congressional district and one at-large member. Board members are appointed by the Governor, with the advice and consent of the Senate. The Chairman of the Board is the at-large member and serves at the pleasure of the Governor. The Commissioner is hired by and serves at

the pleasure of the Board.

The Department is the primary advisor to the state in matters pertaining to public health. It has the power to make and enforce rules and regulations for the protection of public health and the environment. The rules and regulations enacted by the Department have the force of law and affect many aspects of the daily life of citizens. A broad range of health and environmental responsibilities are specifically assigned to the Department by law.

State level responsibilities for Title V rests within the Health Services Deputy Commissioner Area of DHEC. Central operations of DHEC are located in the state capitol, Columbia, S.C. Oversight of all Title V program components is provided within the Bureau of Maternal and Child Health (BMCH) within Health Services: Preventive and Primary Care Services for Pregnant Women, Mothers and Infants; Preventive and Primary Care Services for Children and Adolescents; and Systems of Care for Children With Special Health Care Needs. Additionally, the BMCH operates the Women, Infant, Children (WIC) Supplemental Food Program, BabyNet (P.L. 102-119 of IDEA), and Family Planning (Title X), which are fully integrated into MCH services across the state.

Present Day Structure

In January, 2000 a major reorganization of Health Services within DHEC became effective, under the leadership of Dr. Lisa F. Waddell, Deputy Commissioner for Health Services. Within Health Services four Assistant Deputy Commissioner areas were created: District and Professional Services, Public Health Services, Health Regulations, and an area comprising some Administrative Services, Underground Storage Tanks, and Drug Control. The majority of administrative functions (including financial monitoring of the Title V Block Grant) have been retained within Health Services Administration. A policy unit was also created (Office of Policy and Intergovernmental Affairs) that provides policy and planning support for all of Health Services.

Within the Assistant Deputy area of Public Health Services are six Bureaus: MCH, Disease Control, Home Health and Long Term Care, Community Health, Environmental Health, and Epidemiology. The primary coordination and implementation of all MCH programs is done within this Assistant Deputy Area, in conjunction with the Deputy Area of District and Professional Services, where the public health districts and professional, discipline offices are located.

Bureau of MCH

The Bureau of MCH has the primary responsibility and oversite for Title V programs in the state. The Bureau will provide the coordinated focus for maternal and child health populations for priority setting, planning and policy development for the agency. The Bureau will assure communication and integration of efforts across Health Services program areas that affect MCH populations; enable creative thinking to improve health outcomes and

achieve state and national objectives for all women, children, youth and adolescents; work with Health Services management to develop a process to establish priorities; and assure consistency in messages affecting MCH populations, i.e., assessments, problem statements, evaluations, service delivery, and program implementation. The Bureau Director for MCH position is currently vacant and while recruitment takes place, is being filled by the Acting MCH Bureau Director, Linda Price, who is also the Director of the Division of Children with Special Health Care Needs. The following Divisions and programs are located in the Bureau: Women and Children's Services, Children with Special Health Care Needs, BabyNet (part C), WIC, Title X, Perinatal Regionalization, Fetal Infant Mortality Review (FIMR), and Community Systems Development. Primary data and assessment responsibility for the MCH populations, including lead responsibility for the 5-year MCH needs assessment, lies within the Bureau of Epidemiology and its Division of MCH Epidemiology.

The present day structure of Health Services more closely resembles the organization of the agency three years ago, when there was also a MCH Bureau with similar programs within its domain. At that time, however, the MCH epidemiology functions were within the Bureau. Another difference today is that Health Services has developed the MCH Team that provides a forum for cross-program interaction and coordination among all of Health Services.

MCH Team

With the recent reorganization of Health Services, the purpose of the MCH Team will evolve. Primary responsibility for monitoring the Title V performance measures and the coordination of the various "core" MCH programs has now moved to the BMCH from the MCH Team. An essential service that the <u>Team</u> will now play will be one of coordination between the Bureau of MCH and the other Bureaus and programs within Public Health Services, including:

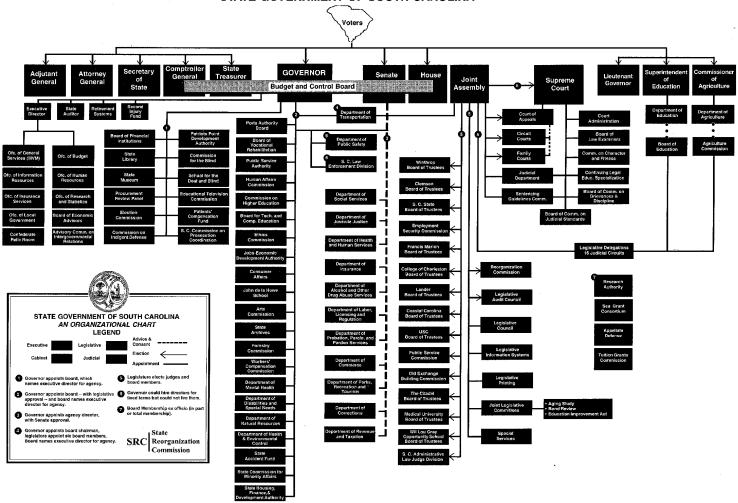
- C Bureau of Community Health (Division of Injury Prevention, Division of Chronic Disease, including Women's Health, Division of Community Development, and the Division of Adolescent and School Health);
- C Bureau of Epidemiology (Division of MCH Epidemiology and Division of Chronic Disease Epidemiology);
- C Bureau of Disease Control (Division of STD/HIV, Division of Immunization);
- C Bureau of Home Health and Long Term Care (Division of Home Health).

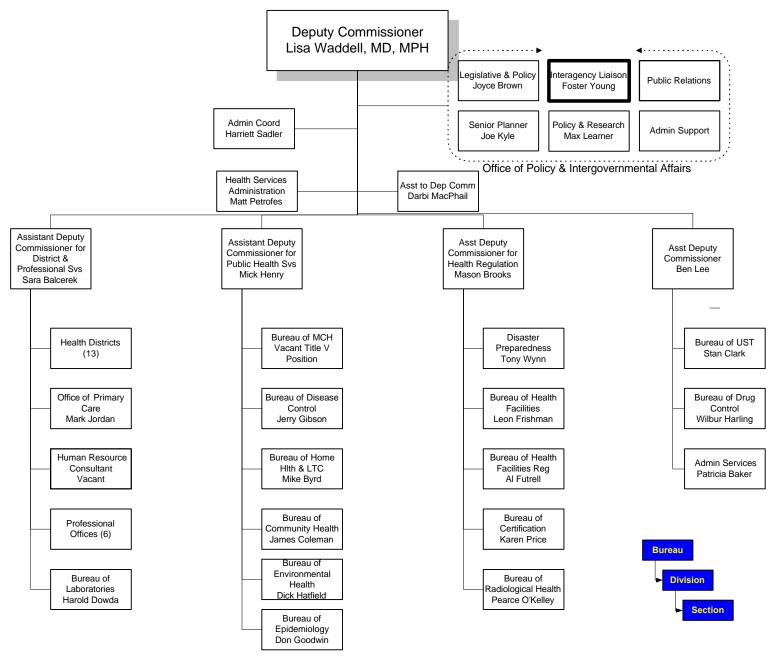
Representatives of these various Bureaus, Divisions and programs are on the MCH Team. The Team will continue to meet monthly.

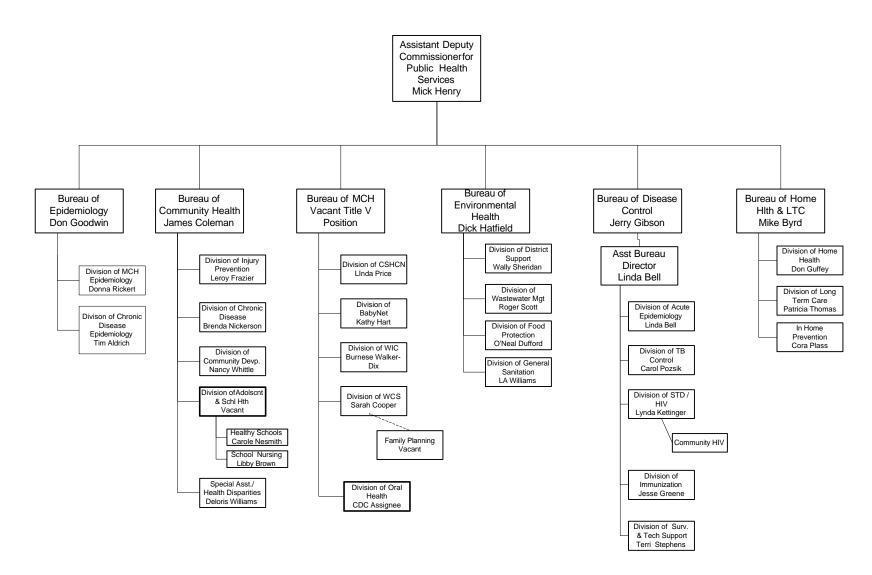
Organizational Charts

Following are three organizational charts: 1) The structure of South Carolina's state government from the Governor down to the Department of Health level; 2) The structure of DHEC from the Commissioner down to the Division level within Health Services; 3) The structure of Health Services which highlights programs that work with the Title V populations and which are referenced in this document.

STATE GOVERNMENT OF SOUTH CAROLINA







June, 2000

Note: Baby Net is a section in the Division of CSHCN

RELEVANT STATE STATUTES TO TITLE V PROGRAM AUTHORITY

Almost every year, legislation is passed that involves new responsibilities and expands the Department's authority to meet perceived needs of the public. In addition to the responsibilities mandated by the State, the Department performs a wide range of activities under Federal authority, in accordance with Federal laws and regulations. Among the programs operated under Federal and State authority are chronic disease, communicable disease, maternal and child health, family planning, health education and risk reduction, environmental sanitation, air quality control, radiological health, hazardous wastes, water pollution control, water supply, emergency medical services, home health, personal care services and primary care. A summary of legislative and congressional statutes providing authority for MCH programs is on the following page.

OTHER RELATED AND EMERGING LEGISLATIVE ISSUES IN FY 2000

The Department of Social Services (DSS) and DHEC have maintained a collaborative working relationship since October, 1995 when the state welfare reform bill was implemented to provide preventive health education and facilitate access to clinical and supportive services to Family Independence (FI) recipients.

A member of the Office of Policy and Intergovernmental Affairs in the Health Services Deputy area, serves as the agency's liaison with FI program staff at the state level. Members of the DSS Office of Family Independence serve on the *Healthy Child Care South Carolina* Steering Committee. The DHEC liaison serves on the DSS Advisory Council to the evaluators of the "County Grants Fund Program for Adolescent Pregnancy Prevention Initiatives", a \$10.5 million TANF initiative funded by the state legislature in 1999.

At the county level, local DSS and DHEC staff work together to coordinate and facilitate information and services provided to clients of both agencies. DHEC staff continue to provide family planning and parenting training to FI recipients in Family Life Skills classes in several locations across the state.

During the 1999 legislative session, \$20 million was appropriated for the Governor's early child care initiative, *First Steps to School Readiness*. This comprehensive, results-oriented initiative has created local partnership boards in all 46 counties. Their purpose is the assure the most efficient use of all available resources, and to eliminate duplication of efforts to service the needs of young child and their families. In order to accomplish the purpose, communities must reach five (5) defined goals: (1) provide parents with access to the support they might seek and want to strengthen families and to promote the optimal development of their preschool children; (2) to increase comprehensive services so children have reduced risk for major physical, developmental and learning problems; (3) to promote high quality preschool programs that provide a healthy environment that will promote normal growth and development; (4) to provide services so all children receive the protection, nutrition, and health care needed to thrive in the early years of life so they will arrive at school ready to learn; and (5) to mobilize communities to focus efforts on providing enhanced services to support families and their young children so as to enable every child to reach school healthy and ready to learn. To date, 45 of the 46 counties have Level I

planning grants in place and one county has just received a \$2 million Level II implementation grant. \$30 million is requested in the 2001 budget.

The end of the Year 2000 legislative session saw the passage of the "Universal Newborn Hearing Screening and Intervention Act". This act requires DHEC to establish evaluation and intervention procedures and services, to establish screening reporting procedures for hospitals, audiologists, and early interventionists, and to establish monitoring and measurement of the screenings and interventions for effectiveness. The legislature also appropriated resources for the previously authorized expansion of SCHIP to 165 of poverty.

"The South Carolina Youth Smoking Prevention Act" also passed in the 2000 legislative session. This bill requires a partnership between DHEC and the Department of Alcohol and Other Abuse Services (DAODAS) to develop and implement a youth smoking prevention plan for the purpose of preventing and reducing cigarette smoking by minors. The initiative is being funded with tobacco product manufactures settlement dollars awarded to South Carolina.

LEGISLATIVE AND CONGRESSIONAL STATUTES

AUTHORITY	RESPONSIBILITY AND TARGET GROUPS	
A. Title V (Federal) Social Security Act	To provide for (1) health services for mothers and children to reduce infant mortality and the incidence of preventable diseases and handicapping conditions among children, (2) rehabilitative services for blind and disabled children under the age of 16, and (3) treatment and care of crippled children.	
B. Title X (Federal) Public Health Service Act (FAMILY PLANNING)	To make comprehensive, voluntary family planning services readily available to all persons desiring such services.	
C. 44-37-30, S.C. Code of Laws, As Amended (NEWBORN SCREENING)	Promulgate regulations or screening for metabolic disorders in infants.	
D. Section 17 (Federal) (CHILD NUTRITION ACT - WIC)	Provide supplemental foods, breastfeeding promotion and nutrition education to pregnant, postpartum and breastfeeding women, infants and young children.	
E. Section 44-33-10, S.C. Code of Laws, As Amended, Section 39.7, Appropriations Act (1989-90)	Provide education, voluntary screening, genetic counseling and referral services to children and adults with Sickle Cell disease, Cystic Fibrosis and Hemophilia.	

F. Public Law 105-17, Part C, Individuals with Disabilities Education Act, State Law 114 (BabyNet)	To develop and implement a statewide, comprehensive, coordinated, multi disciplinary, interagency program of early intervention services for infants and toddlers with developmental delay and their families.
G. Public Law 89-97, Formerly Social Security Act, (Federal) Title XIX, (EPSDT)	Preventive (well) health services to Medicaid eligible children from birth to age 21 with priority.
H. Lead Poisoning and Control Act (State) (LEAD SCREENING & FOLLOW-UP)	DHEC was mandated to establish a program for early diagnosis of cases of lead poisoning and identification and reduction of sources of lead. Local health departments provide screening tests through the EPSDT, Comprehensive Child Health and WIC programs.

1.5.1.2 Program Capacity

As described in the above summary of the new organizational structure within Health Services, all of the primary programmatic functions and duties of MCH within the agency are conducted within the Assistant Deputy area for Public Health Services, while the local implementation efforts are housed within the Assistant Deputy Commissioner area for District and Professional Services.

Following are descriptions of MCH programs and services in South Carolina paid for in part or whole by Title V, or programs that through their participation on the MCH Team are increasing their coordination with MCH efforts and vice-versa. Where eligibility requires payment for services, the Family Planning sliding fee scale provided in the FY 1996 application is still in use (please see Appendix A, FY 1996 MCH Title V Block Grant application).

BUREAU OF MATERNAL AND CHILD HEALTH

Women and Children's Services Division

The Women and Children's Services Division is organized into three general program areas and several special projects to allow for the best utilization of expert staff and to increase efficiency. All activities are targeted toward improving access to risk appropriate care for pregnant women, infants and children and low income women seeking family planning services. These programs function with the support of an administrative staff and utilization of a multi disciplinary team of consultants (Health Education, Nursing, Nutrition, and Social Work).

- 1. Family Support Services: Services provided to mothers and children in South Carolina have been enhanced through the implementation of a Medicaid contract to provide risk appropriate Family Support Services to all Medicaid eligible populations. These services are key to the ongoing promotion of private public partnerships. Providing these core traditional supportive services enhance the ability of the primary care providers to serve as medical homes for families in the state.
- 2) Family Planning: Services are provided statewide according to the regulations and guidelines of Title X of the U.S. Public Health Service Act and include the following: physical examination, contraceptive of choice with counseling, and other services. South Carolina has a Family Planning waiver in place which extends eligibility for FP services to include coverage for Family Planning services to all women up to 185% of poverty regardless of their child bearing status. FP Outreach efforts are fully operational and ongoing outreach is provided to teens and patients whose prenatal care was provided in either the public or private sector.
- 3. Low Risk Maternity Program: The Maternity Program offers an array of interdisciplinary services including primary prenatal care in areas where other care is not available and Family Support Services (including care coordination, social work, nutrition, and health education services). Services are based on a comprehensive assessment of the pregnant woman's individual risk specific needs.
- 4) High Risk Perinatal Program/High Risk Channeling Project: The High Risk Channeling Project has been amended (as of FY 1996) to include risk assessment care by an OB-GYN and delivery in a Level II or III facility. The Family Support Services contract provides all support services to include risk assessment, care coordination, social work, health education, and nutrition services based on the client's individual risk specific need in addition to medical status. Patients who do not have Medicaid coverage may still receive prenatal services paid for through the High Risk Perinatal Program. The majority of the latter clients are immigrants, predominately of Hispanic ethnicity.
- Child Health Services (CHS): Child Health services are provided for non-Medicaid children who use the Health Department as their primary care provider of well child services. These children receive limited or comprehensive services depending on need. Medicaid children are provided the same services through the EPSDT program and all children are risk assessed for educational, nutritional and psychosocial need for Family Support Services. Services include follow-up for missed appointments, coordination and reinforcement for the primary/acute care, linkage to medical homes where available, social work assessment and treatment, nutritional counseling, and parent/child education relative to developmental, safety and environmental issues.
- 6) Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) and Outreach Workers:

DHEC is one of many providers of EPSDT services in the state. Services are the same as those described in comprehensive child health services. Since EPSDT is directed towards identifying conditions that need follow-up and diagnosis and treatment, outreach activities are important to increase participation in the EPSDT program and support continued participation of a child to ensure that necessary treatment is received. DHEC, through a contract with the Department of Health and Human Services (DHHS), provides EPSDT outreach activities (primarily home visiting) to assure that all children get and keep appointments and eligible recipients are enrolled whether the child is a DHEC client or seen by other providers. As of July, 1999, this contract was revised to prioritize outreach by nurses in a more proactive way targeting new eligibles. With the SCHIP expansion, these new eligibles can greatly benefit from initially receiving comprehensive education about EPSDT. Key to this effort will be linking new eligibles to medical homes.

- Pediatric Clinic: Pediatric clinic is for children requiring additional diagnosis and treatment but who do not have a primary care provider other than the health department. The clinic is staffed by physicians and/or nurse practitioners. The range of services offered is dictated by the capability and resources of each health department as well as the needs of the community.
- 8) Partnership Development: To accomplish the MCH goals for women and children there is a continued focus on the development of private public partnerships in which the local physician practices provide the medical care and the health department provides preventive and supportive, core public health enabling services based on the unique needs of the local community. Originally funded through the Child Health Initiative and later through a Robert Wood Johnson grant, partnership activity continues with administrative support from the state Medicaid agency. After the original four pilot partnership efforts, partnership expansion, especially those supporting medical homes for children, have continued to expand. To date, there are a total of 100 partnerships statewide in which the local community decides how best to provide the families a medical home. The partnerships are primarily with Private Primary Care Providers (75 percent), 24 percent with Federally Sponsored or Rural Health Clinics, and one percent with hospital outpatient departments. There are a total of eight models of partnerships, but all partnerships depend on the provision of Family Support Services to enhance and complement the medical home concept.
- Postpartum/Newborn Home Visits: All infants born to women who are on Medicaid are eligible for a postpartum newborn home visit. During the visit, the infant's health status is evaluated through a physical appraisal and weight check. Infants are put on WIC and a "two week" clinic visit is planned. Mothers are encouraged to have a primary care provider and to maintain routine well care and immunizations for the infant. Health education and referral to community resources are provided as needed. The mother's health status is also evaluated as well as the physical environment to determine

if problems exist that would be detrimental to the health of the infant. A follow-up visit or referral for Family Support Services is made if the assessment indicates a need. In 1998-1999, South Carolina has been piloting a newborn home visit to non-Medicaid mothers. The program hopes to expand and make this non-Medicaid visit available in other areas where indicated, and several initiatives including the Governor's First Steps program may make this a reality.

Another pilot just starting is the Healthy Families South Carolina, an intensive in-home intervention program for young families designed to promote optimal child development and well being. It is an adaptation of the Healthy Families America Model. This intervention, which is to be piloted in five counties, includes as a key component a newborn post partum home visit. This visit will be made available to all new mothers and their infants regardless of payment source and will be done for the purpose of assessing strengths and resources and need for additional support to be provided on an ongoing basis. Depending on the family, the level of intensity of follow up will vary but this visit will be a pivotal part of the intervention .

- Lead Screening and Follow-Up: The central office of Children's Health maintains a statewide registry of cases of child lead poisoning, and monitors and classifies all test results analyzed in DHEC and private laboratories. Other services include coordination of follow-up for lead testing and diagnosis, contractual arrangements with the Bureau of Environmental Sanitation for environmental investigation for sources of lead, and provision of specialty medical consultation for private providers. Local health departments provide annual lead testing and follow-up tests to children ages 1-6 years of age who are seen for comprehensive services. Screenings are also provided in the community as requested. Environmental investigations and education regarding abatement procedures is also provided for all cases of lead poisoning. Beginning in 1999, all WIC one and two year olds are being screened for lead, which will soon provide prevalence data for more targeted interventions.
- Newborn Screening: The Central office of Children's Health maintains a statewide registry of patients with PKU, congenital hypothyroidism, galactosemia, congenital adrenal hyperplasia and hemoglobinopathies; monitors laboratory tests; and reports results to providers with recommendations for follow-up. Local health departments and Children's Rehabilitative Services (CRS) clinics provide medical follow-up, distribute special formula for patients with PKU, and supply medications for patients with sickle cell disease and CAH. DHEC has clarified with all delivering hospitals and the State Perinatal Board that responsibility for follow-up of infants retested in the private sector rests with that private provider.
- 12) **Day Care Screening**: Child development centers licensed by the Department of Social Services can receive Social Service Block Grant funds for health screening of children in the centers. These

centers can contract with local health departments to do the screening. Health screening services are the same as those provided through CHS and EPSDT.

- Sudden Infant Death Syndrome (SIDS) Follow-Up: Grief counseling is offered statewide by specially trained and licensed social workers and referrals to support groups are made for families who experience SIDS. In addition, training for first responders is available, public awareness is conducted about SIDS and the need for autopsies is promoted.
- Dental Health: Children's Health strives to assure that all children have access to quality dental care through an integrated network of services including health promotion, oral health examinations, appropriate preventive care and age-appropriate health education (especially through EPSDT screenings and Family Support Services). Beginning in 2000, Medicaid increased reimbursement to dental providers, and DHEC is responding by increasing partnership efforts with the dental community. The state has concluded negotiations with HRSA that will establish the Division of Oral Health within the MCH Bureau, with a Public Health Service dentist serving as the State Dental Coordinator.

Division of Children with Special Health Care Needs

CRS Section

Administration of the Title V program for children with special health care needs is the responsibility of the Children's Rehabilitative Services program (CRS) within the Division of Children with Special Health Care Needs. The CRS program serves over 12,500 children in S.C. between the ages of birth through 21 whose family income is less than 225 percent of poverty. The program provides diagnostic and treatment services including inpatient care, for the following conditions (but not limited to) for children with disabilities and chronic illness: diseases of the bones and joints; congenital anomalies; cardiac defects; rheumatic fever; hearing disorders; epilepsy/seizure disorders; hemophilia; cleft lip/palate; other craniofacial anomalies; cerebral palsy; residuals of trauma; sickle cell disease, and other central nervous system disorders.

The goal of CRS is to provide multi disciplinary rehabilitative and habilitative services to help achieve the greatest potential for children with disabilities and chronic illnesses. In providing these services, CRS recognizes the importance of early intervention and treatment to achieve the best outcome and to reduce the chances for further disability.

In compliance with the regulations for Title V, each state defines the scope of its CRS Program. In South Carolina, a child with disabilities is defined as "an individual below the age of 21 who has a chronic illness or disability which may hinder the achievement of normal growth and development." CRS provides diagnostic, treatment and follow-up services that would otherwise not be available or are inadequate to meet identified

needs. Applications for services, including camp, are made through county health departments. Services purchased outside of DHEC must be preauthorized by the CRS clinic. The following services are offered:

- Clinic services, including evaluations, diagnosis and treatment
- Orthopedic and rehabilitative equipment and, hearing aids, consultations with medical specialties, etc.
- C Medicine, medical supplies and special metabolic formulas
- C Speech, physical, occupational and recreational therapy
- C Summer camp at Camp Burnt Gin in Sumter County
- Coordination of care
- Other services, when ordered by a CRS consultant, may include surgery and corrective or restorative dentistry and orthodontics
- C Family Support Services, including social work, nutrition, health education and family training
- C Parent support

Specialty care is available around the state via the system of CRS clinics and through six tertiary level hospitals and two proximate out- of-state centers (Charlotte and the Medical College of Georgia in Augusta). CRS funds community-based care by operating local clinics throughout the State. Specialized multi disciplinary clinics are made available as close as possible to the home county of the child. Pediatric subspecialty physicians from the Medical University of South Carolina, the University of South Carolina, and Greenville Hospital Systems, travel to several local communities to hold clinics that decrease transportation concerns for CRS families. Subspecialty health care needs of these children are assessed in clinics and followed-up through development of treatment plans and coordination of care.

In order to maintain an optimum state of health, to prevent development of secondary health conditions, and to maintain a child at the highest functional level, Family Support Services (FSS), are available for CSHCN through all thirteen health districts. FSS providers include nurses, social workers, and nutritionists who have received specialized training to work with CSHCN and their families. FSS may be provided in the clinic, home, school, or day care setting. Each FSS provider develops a service plan with the family; every effort is made to coordinate with other agencies and providers. In addition, all FSS providers work very closely with the primary care physician and the subspecialists providing care to CSHCN.

CRS staff are serving on local Interagency Coordinating Councils to ensure that services are being coordinated across agencies for children when all the agencies serving the child come together to an IFSP to plan services for the child.

In an effort to identify medical homes for children served by the CRS program, CRS continues to update and distribute a Physician's Manual to pediatricians and medical specialists in the state to insure understanding of

and easy referral of children to the CRS program. CRS Coordinators and the CRS Medical Consultant continuously visit local physicians to develop partnerships for medical homes for CSHCN.

Additional CRS Initiatives:

- 1) Parent Advisory Council: Coordinating the parent efforts for both CRS and BabyNet (early intervention), this group meets quarterly. The role of the Parent Advisory Council has expanded to included several initiatives important to parents including: development of a *Personal History Folder* that is basically a medical record that the parent can keep on their special needs child; development of a *Family Information Packet* to be given to new families entering CRS services; development of a parent satisfaction survey; and, a parent newsletter has been developed called "Children Are Special." Council members are active at the local level in addition to providing support to state committees addressing SSI, transition and health care reform issues for CSHCN. Additionally, these individuals are active in helping parents understand their right to advocate for their child. Training has been conducted in all 13 health districts to help parents develop support systems. Additionally, Parent Resource specialists are employed in all 13 health districts; these parents of CSHCN staff the Parent Advisory Council.
- 2) Parent Support Groups: CRS, BabyNet, the Department of Disabilities and Special Needs (DDSN) and Family Connection have come together in a statewide initiative to make sure that there is at least one general support group in each health district (13). CRS is contributing a budget of \$200 to each group to help with costs of mailing, speakers, etc, channeled through Family Connection. In some areas, DDSN is providing transportation. BabyNet and EI-TAC are providing technical support as well as training. Family Partners are working with the CRS Parent Advisors to ensure these groups are a success and are working in local CRS clinics. CRS is beginning an initiative to hire parents to work in the CRS clinics.
- Institute in Ohio, and CRS to provide children with special health care needs coordinated services.

 Currently, this project is caring for over 500 children. These services include triaging care of children who are entering and exiting the tertiary and locally based systems of care through identification, referral and service or care coordination. CHOICES is a model for health care reform. It is an example of systems development between public and private sectors to improve the health status of fragile children by reducing access barriers, duplication and gaps in service provision through more efficient resource utilization. This project won the American Hospital Association's highly prized NOVA award. Based on the successful CHOICES model, CRS has established a contract with Medicaid to expand the collaborative care model (see Systems Development below) with

several tertiary hospitals. CRS is a part of the "Healthy and Ready to Work" transition grant with CHOICES.

4) **Systems Development**: In addition to local specialty care clinics, CRS has developed several partnerships with tertiary specialty clinics: neurology, cystic fibrosis, nephrology, endocrine/metabolic and cardiology. CRS nurses are housed in these clinics to provide outreach, child find, appropriate triage and linkage, and coordinated/continuous care. Currently, CRS maintains 27 partnerships and is planning 3 additional partnerships for 2000.

CRS continues to participate in a partnership project to provide a medical home for special needs children in Richland County by providing a pediatric nurse practitioner to coordinate care for CRS children. This project has been undertaken because of the lack of primary medical home providers for children with special health care needs. About 65 percent of the 1,000 patients enrolled in the CRS program in this county are funded through Medicaid. The remaining 35 percent are unfunded. A small percentage of these children have third party pay. Even though Richland Memorial Hospital is charged with provision of care for indigent children, the care may be provided through the emergency room without the benefit of pediatric expertise, through general pediatric clinics without the benefit of coordination, or through inpatient hospitalization. The lack of coordination leads to increases in unnecessary emergency room use and inpatient hospitalization because of a lack of appropriate preventive care.

All patients in Richland County enrolled in CRS are eligible for the program. It is explained to parents at enrollment or during general pediatric or sub-specialty clinic visits. The Department of Pediatrics at the University of South Carolina School of Medicine, housed at Richland Memorial Hospital, has agreed to provide all services of a medical home for Richland County CRS patients. These services include general health care, including sick baby visits 24 hours a day, seven days a week; EPSDT, immunization and health maintenance; urgent and emergent care, and inpatient hospitalization. In addition, intensive coordination of care is provided by a nurse case manager who assures service utilization. In the third year of the partnership, over 120 CSHCN have been provided medical homes. There has been a documented reduced number of hospitalizations and Emergency Room visits among children enrolled in the project and increased continuity of care.

- 5) **The Ryan White program** for children who are HIV positive has been transitioned to the Division of STD/HIV; CRS continues to coordinate with this Division.
- 6) Child and Adolescent Service System Program (CASSP): Through a signed Memorandum of Agreement with S.C. Vocational Rehabilitation to cross train service staff, coordinated care and

provision of collaborative services and treatment plans where appropriate are conducted. In addition, CRS has hired a transition coordinator who is responsible for working across agencies to effectively transition CSHCN into the community. Referrals to South Carolina Vocational Rehabilitation have increased.

- Camp Burnt Gin: The Section of CRS operates a summer camp for children with special health care needs sponsored by state appropriation and Title V funding. Since 1945, the camp, located in Sumter County, has been offering recreational opportunities for children with physical disabilities. Camp Burnt Gin attempts to provide the kinds of experiences and stimulation that will help develop physical, social, and emotional growth in it's campers. It celebrated it's 50th anniversary in 1996. Camp Burnt Gin has developed a special adolescent session, with a unique curricula. Camp Burnt Gin has also provided additional camping opportunities for children who are HIV positive and for children served by the Muscular Dystrophy Association. Camp Burnt Gin is also planning an adult session, for young adults 19-25 years old, in coordination with Easter Seals.
- 8) Cultural Sensitivity: CRS provides access to interpreters when requested and available for individuals whose native language is other than English, or for sign language interpretation for the deaf.

In addition to the services described above, the following includes a description of other services available. Planning for all children, including those with special health care needs has been fully integrated into the CRS operational plan. During the annual planning process across MCH services, Districts are asked to report the number and type of specialty clinics being offered each month to assure that adequate access to specialty care is available at the local level. They are asked to describe their discharge planning activities to assure linkages back to community systems and to describe all partnership initiatives.

9) Supplemental Security Income/Disabled Children's Program (SSI/DCP): The Amendment of Title XVI of the Social Security Act of 1976 (PL 94-566) established a program for children receiving Supplemental Security Income to receive appropriate medical, educational, developmental, rehabilitative, counseling and social services through coordination with other state agencies. The Governor designated DHEC as the state agency to coordinate activities. This effort has now been incorporated into CRS utilizing Title V Block Grant funds; SSI recipients are also eligible for Medicaid benefits. More specific information on the coordination of services and OBRA '89 changes is included under Section IV of this Block Grant Application. CRS has a multi-agency workgroup with 20 agencies to facilitate interagency coordination and SSI outreach to the more than 5000 annual Title XVI referrals. CRS triages all referrals to local CRS clinics and other appropriate agencies who need to be involved.

Transition System: The State CSHCN Program has chosen to develop a transition system, which includes a plan for transitioning CSHCN through various stages from birth to 21, the development of transition criteria, and the development of resources and information needed by families to transition successfully to services in the community.

The SC State CSHCN Program to date has met this goal through the development of transition criteria (see state performance measure #5); the formation of a transition focus group that is in the process of developing transition outcomes and interventions; collaboration with the Kentucky Commission for CSHCN in the development of transition information and strategies; and a joint effort between the Parent Advisory Council and the Transition focus group to develop information needed by families. The SC State CSHCN Program met the goal at the end of fiscal year 1999. Through the year 2003, the goal will be to maintain and enhance a transition system of care.

Adult Hemophilia, Sickle Cell: The State Legislature has appropriated funds for adults with Adult Hemophilia and Sickle Cell Disease to receive certain services through CRS. Guidelines for services are as follows:

Hemophilia: Persons 21 years and older with incomes at or below 250 percent of federal poverty can receive blood products and supplies at no cost; those with incomes above 250 percent of poverty can purchase blood products and supplies at the state contract cost.

Adult Sickle Cell Disease: Persons 21 years and older with income at or below 200 percent of federal poverty can receive limited services.

A Sickle Cell Workgroup operates at the state level comprised of representatives from the four sickle cell community based non-profit organizations in this state; CRS- the state Title V program; Newborn Screening; and DHHS. The group serves as a forum where information is shared, concerns are addressed and funding mechanisms are coordinated. Some key outcomes from the group include: development of a Strategic Plan for services; purchase and statewide placement of billboards about sickle cell disorders and development of several educational materials. A program director works closely with the Sickle Cell Foundations and the teaching hospitals to enhance the system of care for Sickle Cell patients in the state. The director is in the process of developing a statewide registry with all involved tertiary hospitals and the Sickle Cell Foundations.

12) **Genetic disease Testing and Counseling:** Federal funds are channeled through CRS to support three (3) Regional Genetic Centers in South Carolina. These centers provide genetic evaluations and

counseling to children needing this service with income less than 150% of the federal poverty level.

Newborn Hearing Screening: The Newborn Hearing Screening program is housed in the Division of CSHCN. 8 pilot hospitals are currently screening close to 95 percent of their births; it is anticipated that by July, 2000, additional hospitals will be participating resulting in almost two-thirds of all births in the state being screened. DHEC is coordinating efforts to introduce legislation mandating universal newborn hearing screening in all hospitals in the state.

BabyNet (Part C of IDEA) Section - System of Early Intervention Services

BabyNet is South Carolina's system of early intervention services for infants and toddlers with developmental delay, and their families. BabyNet, in accordance with Federal Public Law 105-17 (Part C) provides a comprehensive, coordinated interdisciplinary multi-agency system of services which are delivered in a child's natural environment to the extent possible. DHEC continues to serve as lead agency for BabyNet as appointed by the Governor of South Carolina. The State Interagency Coordinating Council (State ICC) advises and assists DHEC through committee work in policy development, resource development, personnel development, services development, and local community development. Parents, providers and key administrators from state agencies serve on this Council. Services include: evaluations and assessments, audiology and vision services, speech therapy, PT, OT, nursing, health services, nutrition, mental health counseling, assistive devices, transportation, psychological services, special instruction and social work. New initiatives include the Universal Newborn Hearing Screening project which is being piloted in eight hospitals. Additional information can be accessed through the BabyNet website: SCBabyNet.org

Division of Perinatal Systems

This Division has just been created and will serve as the focal point for various perinatal health issues in the state including regionalization, MCH hotline, the Fetal Infant Mortality Review process (FIMR), maternal mortality review, infant mortality review, and increasing access to care for pregnant women. The Division will also work closely with the Division of Community Development within the Bureau of Community Health to ensure that the ongoing community development efforts in the state are linked closely with the MCH systems efforts. Programs within the Division include:

1. **Perinatal Regional Systems Development**: The Agency provides resources to strengthen the Perinatal Regionalization System, including tertiary care centers to impact infant mortality. Six regional centers serve all geographic sections of the state. The system includes four perinatal regions, which include Level I (basic), Level II (specialty) and Level III (sub-specialty) services. To support perinatal systems development, each regional center has a Regional Systems Developer and Obstetrical and Neonatal Outreach Educators who work with all providers and hospitals within the region. DHEC has facilitated the development of written Memorandum of Agreement between the

Regional Perinatal Centers and referring hospitals. A State Perinatal Board, chaired by the DHEC Commissioner, and four Regional Perinatal Boards continue to provide leadership in assuring a risk-appropriate system of care to improve the health of all women and children. Activities also include the collection, analysis and dissemination of perinatal data.

- 1-800-868-0404 South Carolina's Maternal and Child Health Hotline: The CARE LINE is a toll-free statewide hotline which provides assistance and support in gaining access to prenatal care, infant and child health care, assessment and care for children with special needs, family planning services and other related services to South Carolina women, their significant others, and service providers. CARE LINE system's goal is to improve access and enhance health by identifying and resolving barriers to care. The hotline system was able to grow into a more comprehensive system through a partnership of MCH, WIC, March of Dimes, and the Governor's Caring for Tomorrow's Children program. In 1992, CARE LINE was recognized by the U.S. Department of Health & Human Services as one of six model MCH hotlines in the nation. Services include resource information and education and advocacy.
- 3. **Fetal Infant Mortality Review (FIMR):** The fetal and infant review is a community owned, action oriented process that studies fetal and infant deaths to learn how to improve community systems and increase resources to improve outcomes. FIMR has been established in 18 counties in the state for multi disciplinary community-based reviews to identify gaps in the local health care system and address the solvable problems that exist as barriers to improve access to care.
- 4. Children's Health and Safety Councils: The goal of the Children's Health and Safety Council is twofold: 1) to reduce the incidence of preventable, intentional and unintentional, fatal and non-fatal injuries to children birth through 17 years of age and 2) to improve child health by strengthening local systems. The objectives of this initiative are: to increase collaboration and communication at the local and state levels and reduce duplication of services and programs; and to empower local communities to take action on identified issues. There are currently 10 counties participating in this community-based initiative. Key partners in the effort include the State Law Enforcement Division (SLED) and the Department of Social Services (DSS).
- Maternal Mortality Review: All death certificates of women in the state who died and had
 delivered an infant within the past year are reviewed. This effort is coordinated through the South
 Carolina Medical Association MCH Committee.

Division of WIC

WIC is a targeted Special Supplemental Food Program established by Congress in 1972, and federally funded

(USDA) through monetary grants to assist states (DHEC) in safeguarding the health and nutritional well-being of our low income women, infants, and children during critical growth periods. The population served includes pregnant women, postpartum women, breastfeeding women, infants, and children until age five. The South Carolina WIC Farmers' Market Nutrition Program is sponsored jointly by the SC WIC Program and the SC Department of Agriculture. In counties that have a viable and authorized farmers' market, WIC clinics provide coupons on a one-time basis to women and children enrolled in WIC. Clients not only purchase fresh fruits and vegetables at the market, they also learn how to select, store and prepare fresh produce during WIC education classes. South Carolina has worked diligently to assure appropriate integration of WIC services across programs serving low income populations in South Carolina.

Division of Oral Health

DHEC has concluded negotiations with the Health Resources and Services Administration and the Public Health Service (PHS), that will result in a PHS dentist coming to the state for at least two years to serve as the State Dental Coordinator, and the Director of the Division of Oral Health. One of the assignees duties will be to facilitate a statewide oral health needs assessment that will guide oral health planning for the next several years.

BUREAU OF EPIDEMIOLOGY

Division of MCH Epidemiology

This Division has as its mission to work as an effective, multi-disciplinary team providing comprehensive maternal and child health surveillance, analyses, and interpretation of data for policy and decision makers to improve the health of mothers and children in South Carolina. MCH epidemiology provides data and analysis for the MCH Block Grant application and Annual Report. This Division was designed to work closely with the MCH Director and with MCH program and policy staff to ensure that plans and policies are directly linked to evidence that can be evaluated in an ongoing way. In support of this mission, the Division provides professional consultation, technical assistance, carries out research, translates data for individuals and organizations interested in maternal and child health issues, and assures exchange of information with others in and out of the agency. To facilitate planning for the Block Grant, a MCH Five Year Plan has been developed along with annual reports on most of the performance measures, and is being implemented in Districts through their annual planning process.

Primary responsibility for the OBRA '89 requirement to conduct a needs assessment for the MCH populations (including CSHCN) covered under Title V lies with this Division.

BUREAU OF COMMUNITY HEALTH

Division of Injury Prevention

This Division focuses on preventing and reducing the occurrence of injuries and disabilities within the state.

Coordination of DHEC Injury and Disability Prevention activities and the development of partnerships with state and local agencies and organizations that are essential for achieving this mission, lies with this Division.

- Child and Adult Passenger Safety: This program works toward the safe transport of all passengers in vehicles, especially children. The program also works on bicycle safety.
- 2. Traumatic Brain Injury Surveillance (TBI): This program works in partnership with the USC School of Medicine, Department of Disability and Special Needs, and the Budget and Control Board. All hospital discharge records for persons diagnosed with a TBI are shared with the program. The program randomly selects medical records and abstracts data from these records to gain additional information about the injury.
- Emergency Department Injury Surveillance: Similar to the TBI, the ED abstracts a sample of medical records from Emergency Departments.
- 4. Safe Communities Initiative: Consultation is provided to local communities to help define the community's injury problems. The communities are provided with assessment data that helps determine the injury problem in their community. Based on this assessment, community's develop plans to begin to address the identified problems. Funding possibilities are also investigated as part of the planning process.
- 5. Residential Fire Injury Prevention: This program targets communities with a fire injury problem. Smoke detectors are provided to identified homes and follow-up is conducted to assess the presence and functionality of the detector at a later date. The program works with local health departments, fire departments and community organizations to identify, install and assess homes for fire safety

Division of Adolescent and School Health

This Division has just been created and currently does not have a Director. Once fully operational, the Division will serve as the adolescent and school health focal point for DHEC. Strong collaboration with the MCH Bureau will be necessary. Within the Division is the Healthy Schools initiative out of the CDC (position is vacant), and the School Nursing program.

1. School Health Nursing: Health services are available to the school aged population through each

local health department, contingent upon local resources and ability to meet demand. Services available include: health screenings for Medicaid eligible children (EPSDT), immunizations, tuberculosis screening, school nursing services, scoliosis screening, etc. In addition, the Section provides indirect support (including consultation and continuing education) for the delivery of school health services provided by locally employed school health nurses, extending our capacity to serve the school-aged population.

Division of Chronic Disease

Programs in this Division deal with a variety of chronic diseases that affect the MCH populations, in particular women. Areas of emphasis include cancer, heart disease, diabetes, stroke, and osteoporosis and risk factors including tobacco use, nutrition, and physical activity related to these diseases. Of particular relevance are the following:

- 1. Women's Health Program: The Women's Health program was established to integrate program activities that focus on health conditions or diseases that uniquely or disproportionately affect women, including breast cancer, osteoporosis, and heart disease. The program works closely and coordinates activities with public and private partners including the South Carolina Osteoporosis Coalition and the Women's Cancer Coalition. It is also involved in collecting data used as health status indicators for women in South Carolina.
- 2. South Carolina Women's Cancer Coalition Program: This program helps reduce the severe impact of cancer on all women in the state both from loss of quality of life and from death. The SC Women's Cancer Coalition is the primary means to carry out the statewide plan for breast and cervical cancer control in South Carolina, and also provides education, prevention, and advocacy for other major women's cancers such as lung, colorectal, uterine, and ovarian.
- 3. **South Carolina Osteoporosis Coalition**: The SC Osteoporosis Coalition was formed in 1995 through a partnership including such organizations as DHEC, Palmetto Baptist Medical Center, Merck and Company, Hadassah, Alpha Kappa Alpha, Zeta Phi Beta, Columbia College, USC School of Public Health, USC College of Nursing, Midlands Technical College and Wyeth Ayerst Pharmaceuticals. The program is dedicated to educating all people, but especially women and teenage girls, about the threat of osteoporosis, including risk factors, prevention, early detection, screening and treatment. Since 1999, it has helped coordinate the funding of \$100,000 in osteoporosis mini-grants to projects throughout the state estimated to reach as many as 91,000 South Carolinians with education about osteoporosis. Originally a 30-member group, the Coalition became a non-profit organization in 1999, and in the year 2000 has nearly 800 members statewide, including many health organizations, voluntary organizations, and volunteers in communities. It is a partner

with the DHEC Women's Health Program and a member of the National Osteoporosis Foundation.

4. Sexual Assault Prevention and Treatment Program: This program provides technical support to central office and health district staff and customers (primarily adult and adolescent females). The program also conducts research related to intimate partner violence (physical and sexual violence along with psychological abuse) in South Carolina and supports the S.C. Coalition Against Domestic Violence and Sexual Assault as well as 16 rape crisis centers throughout the state. These centers provide prevention and treatment services to survivors in all counties in the state. The program monitors \$1.6 million in state and federal Preventive Block Grant funds earmarked for sexual assault services.

Division of Community Development

Programs in this Division work with organizations, community groups and policy makers at the state and local level to mobilize citizen participation and ownership in developing approaches to improving the health of communities in the state. Social and environmental factors are closely linked and both must be addressed over a sustained period of time. To do this, the community must be equipped with a variety of community based competencies and have adequate support to implement selected strategies. Programs to address these issues include:

- 1. Healthy Communities: The Healthy Communities Initiative is a specially-focused effort to increase community involvement in addressing local health problems. The Initiative provides consultation and technical assistance in Healthy Communities concepts, principles, and strategies; fosters the development of community partnerships; maintains and circulates resource materials; produces a quarterly newsletter; and sponsors a Healthy Communities training program.
- 2. Regional Community Development Specialists: The Regional Specialists work closely with the health districts to provide coordination of community development activities in an assigned region of the state. They coordinate linkages among local agencies, organizations, schools, industries and faith groups at the local, regional and state level. They also provide technical support and guidance to communities regarding training, grant writing, Outcomes Toolkit (a community planning and monitoring software program) and they seek other opportunities which promote community development activities.
- 3. **Health and Faith:** This unit's main focus is on improving the health of families by partnering with the faith community and other community organizations to support and sustain activities towards decreasing infant mortality, improving the health of mothers and children, increasing positive adolescent health behaviors, and improving adult and elderly health. Hold Out The Lifeline, a coalition of faith groups, public and private agencies, and community organizations seeking to assist

families with the tools needed to improve their physical, mental, social and spiritual well-being, is a component of the unit. This unit also provides family health advocate training to enable the faith community and other groups to work alone or collaborate with local agencies and organizations to improve family health. Family health advocates have been trained throughout South Carolina to provide transportation, child care, education, mentoring, friendship and support groups, public awareness campaigns, and other activities targeted to families.

- 4. Community Adolescent Health (Pregnancy Prevention and Abstinence): This program works to assist health districts, agencies, organizations and communities in developing and enhancing adolescent health. The program provides technical assistance and consultation to the MCH Adolescent Health Needs Assessment Task Force, teen pregnancy prevention initiatives and Abstinence Only through education and collaboration.
- 5. CISS Grant for Improved Day Care: The then MCH Community Health Branch applied for and received a CISS Grant in FY 97. The Healthy Child Care South Carolina Steering Committee completed a set of recommendations and strategies for developing an integrated system of care through linkages and collaboration of child care stakeholders in May 1999. The work of this group was concluded in time to coincide with the implementation of the Governor's First Steps to School Readiness initiative. Since then, selected recommendations have been adopted for inclusion on the year 2000 legislative agendas of the Alliance for South Carolina's Children and the Governor's Maternal, Infant, Child Health Advisory Committee. Other public and private advocacy groups have also supported and promoted the recommendations with success.

BUREAU OF DISEASE CONTROL

Division of STD/HIV

The STD/HIV Division provides services to prevent the spread of sexually transmitted diseases (STD's) and HIV infection, to reduce associated illness and death, and to provide care and support resources for persons with HIV disease. The primary activities of the Division are STD and HIV disease surveillance, STD diagnostic and treatment services, prevention counseling and HIV testing, partner counseling and referral services, public information, community interventions, and training. In addition, the Division administers the Ryan White CARE Act Title II, IV and Housing Opportunities for Persons With AIDS (HOPWA) programs which provide drug assistance, medical and support services, and emergency housing assistance to persons with HIV disease.

Prevention services are provided by state and local health departments through contracts with community based organizations. Services are targeted to persons at increased risk for STD's and HIV infection. During 1999, over 34,900 clients attended health department clinics for STD services; over 38,000 clients received HIV counseling

and testing services. Follow-up examination was completed for 1,205 named sex partners of persons with infectious syphilis, and 828 partners of persons with HIV infection were notified.

The STD/HIV Division also operates a statewide, toll-free hotline which provides individual education, counseling and referral services. During 1999, 13,493 calls were made to the hotline.

Medical and Support Services

Federal Ryan White CARE Act Title II funding provides medical care, medications, case management, and supportive services such as transportation, counseling, home health, and nutritional support to eligible persons with HIV disease and their family members. Across the state, eleven local HIV care consortia comprised of community agencies and clinics have coordinated and developed medical care and support services based on identified gaps in service delivery in their communities. A statewide drug assistance program (ADAP) provides FDA-approved medications to qualifying persons with HIV disease.

Housing Services

Federal Housing Opportunities for Persons With AIDS (HOPWA) funding provides emergency housing assistance to eligible persons with HIV disease and their family members. This includes short term mortgage, rent and utility payments. In addition, this program provides operating expenses for a community residence in Greenville. During April 1, 1999 through March 31, 2000, over 2,600 persons with HIV and family members received short term housing assistance and supportive services to prevent homelessness.

Technical Support Section

In order to monitor the STD and HIV infection epidemics in South Carolina, DHEC requires physicians, hospitals, laboratories, and other health facilities to report diagnosed cases to DHEC. The information includes risk factors, age, sex, race and geographic location. Follow-up with persons diagnosed with syphilis and HIV infection is conducted by health department staff to provide partner notification, confidential testing and counseling services, treatment, and referral to medical and support services. Surveillance data is also used to plan and design prevention and care programs to target persons most at risk for sexually transmitted diseases and HIV infection.

Community HIV Prevention Section

Programs in this section focus on preventing the spread of sexually transmitted diseases including HIV infections by building the capacity of local community and health department partners to deliver STD/HIV prevention and education programs.

SC HIV Prevention Community Planning Group (CPG): The CPG was established in 1994 as an advisory
group to DHEC's STD/HIV programs to obtain community input and participation in developing a
statewide comprehensive HIV Prevention Plan. The group has 25 to 30 representatives of state and local

organizations and individuals, agencies and community organizations, and persons affected and infected with HIV.

2. HIV Prevention Collaborations: The HIV Collaborations were created in response to a need identified by the CPG to increase the capacity of local organizations to conduct HIV prevention activities. There are eleven Collaborations in the state. Each Collaboration involves a partnership of anywhere from seven to twenty-five prevention partners. Each Collaboration can choose to target any at-risk population, although there is an emphasis on populations that are disproportionately affected, particularly racial/ethnic minority populations.

1.5.1.3 Other Capacity

Staff Resources and Leadership

A summary of FTE positions by administrative units within Health Services central office that work with the MCH population is provided below.

Health Services

Number of Staff in Full Time Equivalents

TYPE STAFF	Policy and Intergovernmental Affairs	Public Health Service	Administrative Health Services
Managerial/administrative /budget	2	34	4
Administrative Support		25	
Program Director/ Manager		18	
Nutritionists		2	
Social Workers		2	
Health Education			
Nurses		4	
Data and Research Managers		13	
TOTAL	2	98	4

^{*}Not all are slotted FTEs

Following are brief biographies of key leaders within MCH in DHEC:

NOTE: South Carolina suffered a great loss in FY 2000 with the departure of Marie Meglen, Title V Director, from DHEC. Ms. Meglen provided strong, consistent and visionary leadership for over 17 years to the state's MCH efforts. Her absence will be felt. The agency is in the process of recruiting a new Title V Director.

- **Linda Price**: Linda Price has been employed in Maternal and Child Health for the past 21 years. She is at present the Acting MCH Bureau Director. She was Administrator in the old Bureau of Maternal and Child Health for 11 years and has served as Director of the CRS program for the past 11 years.
- **Carole Gibbs**, MPH: Carole Gibbs is a policy advisor in the Maternal and Child Health Bureau, and is staff to the MCH Team. She has worked as a health educator, project administrator and program manager in Maternal and Child Health programs in DHEC since 1979.
- Sarah Cooper, BSN, MSN: Has been with DHEC over twenty years serving at the county, district (in two health districts) and state level. Is ANA certified as an adult nurse practitioner. Has been at the state level for 14 years. For the past six years has been responsible for program planning, implementation, and QA of personal services to reproductive aged women and children, and is the present Division Director for WCS. She is also the agency's team leader/coordinator of the statewide, interprogram interdisciplinary efforts at supporting families in the appropriate use of primary care and the practice of healthy behaviors through Preventive and Rehabilitative FAMILY SUPPORT SERVICES for Primary Care Enhancement.
- **Burnese Walker-Dix,** MS, BS, RD: State WIC Director, employed with South Carolina state government for 17 years: DHEC from 1982-1983, School Food Services at Department of Education 1983-1985 and DHEC since 1985-present. Worked in the WIC Program in two states (Georgia and South Carolina) with 20 years of WIC experience.
- **Luanne Miles,** MSW: Division Director, Perinatal Systems. She has worked with maternal and child health programs at DHEC for the past 6 years. Previously, she worked as a clinical social worker with children and families for 11 years in both private and public health agencies. Currently, she is the Director for the Division of Perinatal Systems and directs perinatal regionalization activities. She also serves as a liaison with the 3 Federally funded Healthy Star projects in SC.
- Elin Holgren, CNM, MPH: Program Manager in the Division of Perinatal Systems. Has 20 years of direct MCH program experience. In Mississippi she was Director of Maternity and Perinatal Services for 9 years. In South Carolina her primary focus has been on systems issues to improve health outcomes through Community Systems Development, Fetal and Infant Mortality Review, and Child Fatality Reviews at the community level. She also provides leadership to the Bureau in Maternal Mortality Review efforts.
- C Donna Rickert, MA, MPH, DrPH: Since July, 1998, Dr. Rickert has been the State Epidemiologist for Maternal and Child Health in DHEC. She has lead responsibility for the annual and five-year statewide comprehensive needs assessment for the Title V Block Grant, and serves as the State Health Department's

evaluator for the Governor's First Steps Initiative to enhance school readiness in South Carolina's children. Her current activities involve using innovative methods to link a variety of health information resources to strengthen health risk surveillance at the state, district, and county level. Prior to this she was employed for eight years as Director of Health Statistics for the Jefferson County Department of Health in Birmingham, Alabama. She has a master's degrees in Psychology and Epidemiology, and a doctoral degree in Maternal and Child Health.

- Joe Kyle, MPH: Senior Planner for the Office of Policy and Intergovernmental Affairs. Has provided policy and planning coordination for Title V for almost four years. Has coordinated the MCH planning process, the Title V application submission, and. various MCH activities (i.e., coordinating Health Services/HRSA negotiations for recruiting a federal dental assignee). He has been with DHEC for four years. Prior to that, he spent eight years in Central America with the Peace Corps managing development projects, and two years at the county health department level in east Texas.
- Joyce Brown, RN, MSN: Served as Title X Family Planning Program Nurse Specialist in Catawba Health District, 1971-1987; State Consultant for Title X Family Planning Program, 1987-1990; and State Family Planning Director from 1990 through the present. Currently is also the Legislation and Policy Advisor for the Office of Policy and Intergovernmental Affairs for all of Health Services. Point person for DHEC on the Governor's First Steps, school readiness program.
- Patsy Myers, M.S., R.D., DrPH: Since May, 1999 Dr. Myers has been the Perinatal Epidemiologist for the Maternal and Child Health Division of the Bureau of Epidemiology. Current activities involve maintaining and analyzing the Perinatal Regionalization Surveillance Database and production of the annual SC Perinatal Regionalization Surveillance Data Book. Other responsibilities include participating in research and surveillance activities pertaining to Maternal and Child Health at the state, district or county level as needed. Her previous background is in Public Health and Clinical Nutrition. She has served as District Supervising Nutritionist in two different districts of the Mississippi Department of Health, and as a local level nutritionist in the State of North Carolina. She has a master's degree in Nutrition and a doctoral degree in Public Health Nutrition with a strong background in epidemiology.
- C 13 CRS Parent Advisory Council members (one per District) are employed part time (16-20 hours per week).

1.5.2 State Agency Coordination

The Department of Health and Environmental Control is a separate state agency from the Department of Health and Human Services (DHHS-Medicaid) which is a cabinet agency of the Governor. As with the rest of the nation, the relationship between Title V and Medicaid continues to evolve. The relationship has been changing at two levels. At the commissioner's level and using task forces, we have worked together to: 1) recruit health care providers; 2) improve reimbursement procedures; 3) improve reimbursement options for providers by developing incentives for providing medical homes, improving EPSDT; 4) expand covered services; 5) increase eligibility

(most recently via SCHIP); 6) change the image of Medicaid to providers and patients; and 7) develop systems of care.

The South Carolina Medicaid agency initially piloted four PEP initiatives to offer partially capitated services through local pediatric and family practices. Evaluation indicates satisfaction of providers and clients, improved immunization rates, higher EPSDT show rates for appointments, and fewer ER visits. By the end of FY 99, there were 43 PEPs and 391 HOPs (enhanced reimbursement practices in return for providing a medical home to clients). DHEC provides upon referral, Family Support Services to assist the clients/families in appropriate utilization of primary care and in healthy lifestyles practices.

The first Medicaid HMO started taking patients in South Carolina in December 1996. This HMO, Select Health of South Carolina, is presently the only Medicaid HMO in the state. They continue to contract with the health department to provide home health services, the post partum/newborn home visit, family support services, and services to CSHCN.

Family Support Services continue to be a main focus of these core personal preventive services provided to individuals and families. The fourth full year of implementation has just been completed and the integration of all service providers across disciplines and other program areas has resulted in a more comprehensive approach to service delivery by an expanded range of providers. More than 50,000 clients were served in SFY 1999.

The following represents a summary of the Medicaid contracts, amendments contracts, and other Memorandum of Agreements between DHEC and DHHS.

Medicaid Mega Contract:

In FY 1996, efforts were taken to consolidate many of the Medicaid contracts into what has become known as the *Medicaid Mega Contract*. During 1998-1999, DHEC and the Department of Health and Human Services have, as a result of a HCFA audit, renegotiated the activities of the Mega Contract. The contract still contains clinical services including Family Support Services as well as administrative services that DHEC provides to support the Medicaid State Plan.

The activities of this contract are categorized into four goals:

Goal 1: To increase provision of Medical assistance to Medicaid eligible individuals and potential eligibles including reproductive aged women at or below 185 percent of poverty, infants at or below 185 percent of poverty, children at or below 150 percent of poverty and or children with special health care needs. The first objective under this goal includes recruitment activities to identify potential eligibles and assist them in becoming eligible for the most appropriate program. All DHEC staff are involved in this effort including outreach workers formally

called Family Planning outreach workers. A second objective under Goal 1, in addition to the recruitment activity, is to assist special needs children in the appropriate use of Medicaid services available to them.

Goal 2: To assist the Medicaid State Plan in recruiting providers to serve Medicaid recipients. This goal goes hand-in-hand with DHEC's desire to promote private public partnerships to assure medical homes for Medicaid recipients and includes the training of Nurses in the private sector in the provision of EPSDT clinical services.

Goal 3: To improve birth outcomes for Medicaid eligible women and infants. The objectives of this goal are carried out through the regional perinatal contracts with the perinatal centers including referral and transport.

Goal 4: To improve health outcomes of Medicaid eligible populations with special health care needs. Activities include the development of a coordinated tertiary hospital/local Medicaid health care service system that targets children with special health care needs. A second objective includes the development of a comprehensive implementation plan to establish a regional system of care for Medicaid eligible individuals with Sickle Cell Disease.

Quarterly meetings are held between DHEC and DHHS to monitor the plans designed to meet the goals. Detailed reports are submitted by each health district and feedback from the Medicaid agency is provided directly to the local health districts, based on their activities and accomplishments.

Across Bureaus:

Family Support Services: This contract was developed in 1995 in response to the desire to work in partnership with private providers in the implementation of Medicaid managed care. It is a fee for service contract to provide Family Support Services to the existing Medicaid eligible population, which will include pregnant women, infants, children and children with special health care needs. This contract gives all health districts the opportunity to provide evaluation of the need for FSS, including nursing, social work, psychosocial, nutrition and education services (including treatment and follow-up as needed), to assist families in the appropriate use of primary care and the practice of healthy behavior. This allows DHEC to provide services to a greater population than is possible with the current population-specific contracts. Districts continue to provide FSS for all populations and for all programs. Efforts are underway to increase FSS outreach and to better determine FSS costs for services provided. These services provide an excellent resource to our partnerships with medical providers as they complement and enhance their provision of clinical services.

Bureau of Maternal and Child Health

2) **Perinatal Regionalization** (Division of Perinatal Systems): The administrative contract developed with Medicaid to assist in improving access to risk-appropriate care for women and infants. Emphasis has

been placed on development of policies which assure referrals and back transport of Medicaid eligible high risk pregnant women and infants.

- 3) **BabyNet Outreach** (Division of CSHCN): To provide outreach services to BabyNet eligible Medicaid recipients and potential BabyNet eligible Medicaid recipients. This function is accomplished by the District BabyNet Coordinators.
- 4) Clinical and Family Planning Services (Division of WCS): Contract which includes all clinical services for Maternity Care, Family Planning and Family Support Services.
- 5) **Children's Health** (Division of WCS): Contract that includes all clinical services for children (EPSDT) as well as Family Support Services.
- 6) Children's Rehabilitative, Clinical and Care Coordination Services (Division of CSHCN): Provides medical services to pediatric patients in the CRS or Children's Health clinics, nutrition, psychosocial services, care giver training, and coordination of services for special needs children through CRS and FSS. Occupational and physical therapy, audiology and speech therapy services are also provided through CRS.
- Purchase and Provision of Hearing AIDS and Accessories (Division of CSHCN): Provides for the purchase and provision of hearing AIDS, hearing aid accessories and coordination of hearing aid repairs for Medicaid eligible children and recipients who are 21 years of age and over and who participate in the DDSN waiver program.
- 8. **Administration and Provision of Orthodontic Services** (Division of CSHCN): Provides for the provision and administration of orthodontia services to eligible individuals under the age of 21 who have qualified under the CRS program criteria.

Other Medicaid Contracts:

Bureau of Maternal and Child Health

- 1. **High Risk Channeling Project** (Division of WCS): Remains a waivered service, but only applies to risk appropriate care and delivery. Support services are included separately in the Family Support Services segment of the Medicaid service contract.
- 2. **EPSDT Outreach** (Division of WCS): An administrative contract to cover outreach services.

- Child Health Maintenance (Division of WCS): An administrative contract to provide training for nurses in private or other public provider settings to perform EPSDT appraisals, and is a part of the Mega Contract.
- 4. **MOA for Provision of State Matching funds for Therapeutic Services/Alpha-feto-protein (AFP) tests** (Division of CSHCN): Provides state matching funds for physical therapy, occupational therapy, speech therapy, and audiology services to Medicaid eligible individuals sponsored by CRS and BabyNet. Additionally, this MOA provides state match for the increased reimbursement rate for AFP tests.
- 5. MOA for Provision of State Matching funds for persons with Sickle Cell Disease/Trait and Enhanced Genetic Services (Division of CSHCN): Provides state matching funds for family planning, genetic education and case management services to Medicaid eligible persons with sickle cell disease/trait and enhanced genetic services provided by genetic centers.

DHEC has been working in various ways to partner with the private medical sector in the provision of MCH health services. With the large indigent health service need, it is not possible for Federally funded health centers, public hospitals, and the health department to meet all of the need. Based on this, the former Public Health Commissioner Mike Jarrett and the current Commissioner, Doug Bryant, worked to change the image of the health department from the provider of indigent medical services, to one of participant in a private/public partnership to complement with Family Support Services the medical services provided. To accomplish this change, the agency has had multiple interagency task forces (Obstetrical Task Force, Newborn-Infant Task Force, the State and Regional Perinatal Boards, and a Pediatric Advisory group), met with state level provider groups, met with local medical groups and community groups, and based on input, modified service operations based on community need.

The agency currently has the following types of relationships with providers and hospitals:

1) contracting for physician services in the health department clinic and/or in their office to provide primary care; 2) contracting for hospital services; 3) contracting along with a hospital for another health agency to provide services; 4) as an access point to enter prenatal care by being screened and referred to the private sector; 5) outstationing of health department staff in provider's offices who provide case management services, nutrition, social work and health education services, after hours call, home visiting, preventive health services (immunizations, well child assessments such as EPSDT), outreach and anticipatory guidance, and; 6) other special arrangements, such as the medical home project for special needs children.

Key Resources/Groups Influencing the Provision of MCH Services

Multiple groups affect the provision of MCH Services. The DHEC Commissioner has promoted the building of

partnerships between agencies and between private and public sectors as one of the most important initiatives to improve services. This attitude has been contagious and has infected most groups and agencies providing health services statewide.

The Maternal, Infant, and Child Health (MICH) Council was established by the South Carolina Legislature in 1986 to improve the health status of pregnant women, infants and children. The MICH Council plans and coordinates the health care services for mothers and children, identifies and creates an awareness of maternal and child health issues, and develops and implements a three-year Service Plan. The MICH Council is housed in the Office of the Governor. The Council is legislatively mandated to perform an annual assessment of health status and the health services delivery system, to develop a 3-year service plan and annual interagency action plans, to implement the plans, to recommend state policies, and to initiate community awareness.

With the election of the present Governor in 1998, there has been an increasing focus on education and the well being of children. There has been a strong emphasis on preschool readiness. All MICH agencies and organizations are engaged in the development of the First Steps initiative. Every county in the state has a First Steps Board comprised of a cross-section of social services agencies, advocacy groups, and the private sector that is coordinating a needs assessment and development of an action plan. DHEC is a strong partner in this effort at the state and local level.

Within the private sector the South Carolina Medical Association (SCMA) and South Carolina Health Alliance (SCHA), the Alliance for South Carolina's Children, Family Connections, as well as the Children's Hospital Collaborative have all been strong partners for promoting improvements in the provision of MCH services.

Other commissions, committees, councils, and task forces provide input and influence the formation of MCH policies and programs and impact the provision of MCH services. Some of these groups deal with broader health issues than just MCH. One such group is the Health and Human Services Coordinating Council (Commissioners of all Health and Human Service Agencies), which has responsibility to coordinate activities for all of Health and Human Services. This group has developed uniform services definitions for use by all agencies and has reviewed the format of case management across all agencies.

Because DHEC is the source for much of the data related to the MCH population and MCH services, it frequently serves in a planning role intra- and interagency. For example, Health Services is very involved in developing the 3-year Service Plan of the Maternal, Infant, and Child Health Council of the Governor's Office, perinatal regionalization is largely coordinated by Health Services, and Health Services staff are playing a key role in the development of the First Steps program.

The Bureau of Maternal and Child Health, Health Services and all of DHEC, have consistently worked with

related Federal and state programs to coordinate services for mothers, infants and children. Coordination takes place in various ways, including: administration, planning and policy development, service provision, funding, and evaluation. Levels of infrastructure include statewide, health district, county, service delivery site, and individual patients.

The Bureau of MCH and other Bureaus within Health Services, have a strong working relationship with various state agencies. Efforts are underway to improve organizational structures, data systems, and client services through a number of efforts initiated through DHEC and these agencies. Several grant programs, such as CISS and SSDI, support an improved framework for service integration. Examples of the plans and activities are:

COMMUNITY AND MIGRANT HEALTH CENTERS: The Office of Primary Care (Health Services) and Migrant Health (Office of Minority Health) are located within DHEC and provide an opportunity for direct coordination on specific programs and issues as needed. Where possible, Health Services and Health District staff plan services at the local level with Federally funded health centers for both preventive and primary care for pregnant women, infants and children. In addition, Health Services reviews and supports perinatal plans for Federally funded health centers. Coordination of service provision varies from center to center.

S.C. DEPARTMENT OF ALCOHOL AND OTHER DRUG ABUSE SERVICES (DAODAS): SC DAODAS is a separate state agency. Coordination of activities takes place on specific issues and/or by program as needed. DHEC is in the process of developing a MOA to formalize and enhance this partnership.

S.C. DEPARTMENT OF DISABILITIES AND SPECIAL NEEDS (S.C. DDSN): The Division of CSHCN and Section of BabyNet work very closely with DDSN in the coordination of care for children eligible for their respective programs. DDSN has worked closely in the development of the delivery system for infants and toddlers with developmental delays and their families. They are an essential partner in the area of care coordination for children with special needs.

HEALTHY START: There are three Healthy Start projects functioning in the state. These are:

- 1. **Pee Dee Healthy Start, Inc.** This project is the successor to the earlier Pee Dee Healthy Start Project sponsored through the SC United Way. The project is now managed through a consortium with 501.c.3. nonprofit organizational status. Project activities focus on rural outreach and the service area comprising Chesterfield, Darlington, Dillon, Marlboro, Marion and Williamsburg counties.
- 2. **Richland Healthy Start**. This consortium is led by Palmetto Health Alliance (Richland Memorial Hospital). Members of the collaborative include Community Health Partners, Eau Claire Cooperative Health, Richland Community Health Care Association, Inc., Benedict College, the March of Dimes, Richland County Health Department and Richland County Department of Social Services. The project goal is to reduce infant mortality

and improve the well being of women, infants, children and families in four targeted zip code areas of Richland County. The project is in its third year.

3. **Low Country Healthy Start**. This project, administered through the SC State Office of Rural Health, is a community-based effort that aims to improve infant mortality and improve pregnancy outcomes in Allendale, Bamberg, Hampton and lower Orangeburg, all predominantly rural counties. The project is in its third year and has utilized contracts with existing agencies as a primary means of expanding and strengthening resources.

STATE CHILD CARE AND DEVELOPMENT BLOCK GRANT (CCDBG): South Carolina's Child Care and Development Block Grant is administered through the Bureau of Community Services at the S.C. Department of Health and Human Services (DHHS). The Bureau of Community Services (MCH Programs Branch) works closely within DHHS in assuring that assistance is available for low income families and that plans are developed which assure safe, affordable day care in all areas of the state. Recently, DHHS made available approximately \$1.7 million in Child Care and Development Block grant funds to support 183 child care providers in 39 counties. These grants included: (1) Implementation grants, up to \$25,000, awarded to start quality infant and toddler services in enhanced or accredited centers enrolled in the ABC Voucher System; (2) Expansion grants, up to \$12,000, awarded to increase the number of infants and toddlers currently being served in enhanced or accredited centers enrolled in the ABC Voucher System; and, (3) Quality grants, up to \$5,000, awarded to improve the quality of infant and toddler services in enhanced or accredited centers in the ABC Voucher System. These grants were awarded for two purposes: (1) to solicit interest and determine basic qualifications of current providers interested in implementing, expanding and raising the quality of infant and toddler programs throughout the state; and, (2) to encourage those providers currently operating at the lowest level of care (meeting state licensing requirements) to raise their level of care to the enhanced or accredited status and to maintain standards higher than current state licensing standards.

The MCH Programs Branch was awarded a CISS grant to enhance collaboration between agencies and providers of child day care to ensure a healthy environment for children in day care. The Director of the Child Development Department for DHHS has served on the Steering Committee of the Healthy Child Care South Carolina grant since it was awarded in October, 1997.

S.C. DEPARTMENT OF EDUCATION: Both the Department of Education (SCDOE) and DHEC at the state and local school district levels play a role in school health. Both agencies have an active role in a CDC funded capacity building cooperative agreement which provides high level of support for enhancing the school health effort. The Bureau of Community Health has a full time nursing consultant whose primary responsibility is to render leadership and direction for school nurses, SCDOE, and local school districts. In addition, BabyNet provides ongoing efforts which work to transition children into preschool programs. DHEC also has a contract with DHHS to provide training to Registered Nurses in the private sector (physician's offices or schools) in order

to expand EPSDT screening services.

PEDIATRIC EMERGENCY MEDICAL SYSTEM (EMS): Pediatric EMS is coordinated statewide by the Division of Health Regulations. Various Divisions that work with the MCH populations work on EMS issues including: maternal and infant transport; local community transportation assessment tool, protocol development, and injury surveillance. Currently, the Division Director for CSHCN participates in planning through the EMS Advisory Committee. CRS staff have also worked closely with EMS staff and tertiary emergency room physicians to develop a portable emergency plan of care for CSHCN.

DHEC continues to maintain appropriate relationships with all the major agencies that work to improve the health and well being of mothers and children. There have been no significant changes to these relationships described in the FY 1999 application except as redefined below:

STANDING ADVISORY COUNCILS/COMMITTEES/TASK FORCES

Various Standing Advisory Councils/Committees and Task Forces exist through which planning and interagency work is accomplished to meet the needs of mothers and children in South Carolina. Examples of these committees are listed in Appendix A (NOTE: This list is representative, not complete).

II. REQUIREMENTS FOR THE ANNUAL REPORT

2.1 Annual Expenditures

See Supporting Documents SD 3.1, 4.1 and 4.2, and 5.1 and 5.2 in the Supporting Documents Section (5.8)

2.2 Annual Number of Individuals Served

See Supporting Document SD 6.1, 7.1, 8.1, and 9.1, in the Supporting Documents Section (5.8)

2.3 State Summary Profile

See Supporting Document SD 10.1, in the Supporting Documents Section (5.8)

2.4 Progress on Annual Performance Measures

South Carolina made progress on many of the 18 core and 10 state performance measures this last year. Following is a description of that effort. Explanations are provided for those measures where improvement is needed, as well as those measures that did not have data currently available to measure. See Supporting Documentation SD 11.CORE.DHC (1991-1995).1 through SD 11.NEG.IB (2001-2005).1, in the Supporting Documents Section (5.8), for a five year projection with year-to-year goals for each performance measure for next year, and Section IV (Annual Plan, 4.1), for program activities intended to reach the target(s). Measures are described here by level of the pyramid, co-mingling core and state measures.

Several measures are being added for next year in the Annual Plan section, while several other measures reported in the Annual Report, are not continuing as performance measures. This shift has resulted from the analysis that came out of the 5-year needs assessment effort. While South Carolina will continue to monitor all of the measures whether included in this application or not (through the implementation of the DHEC strategic and operational plans), the state is prioritizing certain issues that heretofore have not been included in the Title V performance measuring system. All necessary data is provided in SD11 to show progress to date on all of the measures, including those that are included in this Annual Report section and which are not being carried forward in the Annual Plan (Section IV).

Level 1: Direct Health Care Services

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

1) The percent of State SSI beneficiaries less than 16 years old receiving rehabilitative services from the State Children with Special Health Care Needs (CSHCN) Program. (FPM #1). SSI beneficiaries automatically qualify for Medicaid in South Carolina. In 1999, the target of 26 percent of SSI beneficiaries receiving a service from the CRS program in the state was exceeded, as 31 percent of SSI beneficiaries received a CRS service. In those instances where

services were not covered by Title XIX, there were procedures in place to approve services in the same manner as the CSHCN program. Recipients of SSI were also referred to DDSN, School for the Deaf and Blind, Department of Mental Health, and HIV programs; all of these referrals were through a MOA with all the institutions.

2) The degree to which the State Children with Special Health Care Needs (CSHCN) Program provides or pays for specialty and subspecialty services, including care coordination, not otherwise accessible or affordable to its clients. (FPM #2). South Carolina achieved a score of "8" last year (on a 1-9 scoring system) by providing or paying for eight services described in SD #11 (Section 5.8) in the Annual Plan. This score was on target and similar to previous years. Specialty care was made available around the state via the system of CRS clinics and through six tertiary level hospitals and two proximate out-of-state centers (Charlotte and the Medical College of Georgia in Augusta). CRS funded community-based care by operating local clinics throughout the State. Specialized multi disciplinary clinics were also made available as close as possible to the home county of the child. CRS clinics were staffed across disciplines and subspecialties.

CHILDREN

1) **Percent of Medicaid newborns in the state receiving a DHEC home visit. (SPM #1).** South Carolina did not reach the target of 73 percent in SFY 1998, with 54.2 percent of Medicaid newborns receiving a newborn home visit receiving it from a DHEC provider. For 1999 we were able to obtain Medicaid claims data as well. Based on the 1999 numbers, we came closer to the target of 75 percent target, with 68.8 percent (17,293 of 25,119) of Medicaid newborns that received a newborn home visit receiving it from a DHEC provider. Public Health has continued to provide the majority of postpartum newborn home visits in our state, as 11 of the 13 health districts continue to be the primary provider of this service. The districts that provided the visit utilized MCH staff and home health services staff. For the Title V Annual Plan for next year (Section IV), this measure is being modified to include all Medicaid newborn home visits in the state, not just those conducted by DHEC.

We continue to evaluate the feasibility of offering the newborn home visit to all newborns. One county is piloting visits to non-Medicaid infants within one group practice. That project demonstrates a great acceptance of the visit by the families and the primary care physicians involved. Further evaluation relative to the risks identified is being compiled and efforts are also underway to link the newborn home visits with follow up Family Support Services. To further expand the opportunity of this visit to the non-Medicaid families, several public health districts have submitted plans to expand this visit, primarily to the uninsured migrant population, by using Title V dollars made available with some savings realized from our High Risk Perinatal Program.

Level 2: Enabling Health Care Services

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

1) The percent of Children with Special Health Care Needs (CSHCN) in the State who have a "medical/health

home." (FPM #3). South Carolina continues to define this measure as the presence or absence of a primary care provider reported on the CRS charts as a proxy measure for both CSHCN and medical home, recognizing that this is a gross estimate at best of the overall CSHCN population in the state, and that having a primary care provider reported on a chart is only one part of the medical home concept. Using these definitions, South Carolina almost reached the 90 percent target for 1999, as a sample of records showed that 89.0 percent of children in the program had a primary care provider. South Carolina will rely on the results of the national survey, when available, to better measure this critical component of our effort. In FY 1999, the CRS program continued to place strong emphasis on establishing and expanding partnerships with the medical community, working with physicians to increase their acceptance of CSHCNs as patients. Efforts have been in place statewide to improve partnerships with private providers such as pediatricians, sub-specialists, hospitals, universities and children's clinics. South Carolina has some kind of private-public partnership in every health district.

PREGNANT WOMEN AND INFANTS

None to report.

CHILDREN

1) **Percent of Medicaid children under three who have received a primary care service. (SPM #12).** More children received primary care services in FY 1999 compared to FY 1998 (71,986 compared to 69,006), but the overall percentage remained unchanged as the number of children under three grew by a similar amount. South Carolina did not reach its target of 86.2 percent for FY 1999. Partnerships with primary care providers continues to receive strong emphasis. This measure will not be part of the Title V Annual Plan for next year (Section IV), but will continue to be monitored through the DHEC Health Services Operational Plan.

Level 3: Population Based Health Care Services

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

None to report.

PREGNANT WOMEN AND INFANTS

- 1) Percent of newborns in the State with at least one screening for each of PKU, hypothyroidism, galactosemia, hemoglobinopathies (e.g., the sickle cell diseases) (combined) (FPM #4). South Carolina met the target of 99 percent in 1998. All hospitals provided this service by law, and health department personnel followed-up closely all positive results. See SD #6 under Supporting Documents (5.8) for numbers tested, and follow-ups initiated.
- 2) **Percentage of mothers who breastfeed their infants at hospital discharge**. (**FPM #9**). This data is obtained from the newborn screening form. Mothers are asked about their breastfeeding behaviors at the time their infant is screened for metabolic disorders. For 1999, South Carolina improved to 33.7 percent (compared to 32.8 in 1998) of women

reporting exclusive breastfeeding, but we did not reach the target of 35.0 percent. This population data continues to be circulated to all MCH staff for outreach activities and assessment.

- 3) Percentage of newborns who have been screened for hearing impairment before hospital discharge. (FPM #10). South Carolina has made substantial progress in its newborn hearing screening programs. Eight hospitals are now implementing the program, and combined with NICU discharges from the perinatal centers, screened 43.3 percent of all infants in the state during CY 1999. This is up from 4.3 percent just two years ago. The state continues to work with the newborn hearing screening coalition. A comprehensive data system that will enable the state to track all screenings, and equally important, follow-up of patients when appropriate, is being implemented. Legislation has been introduced making the screening mandatory for all occurrent births in the state.
- 4) **Percent of women giving birth with an unintended pregnancy.** (SPM #2). About 46 percent of women giving birth in 1998 reported that their pregnancy was unintended, according to the PRAMS survey. The state met its target of reducing the unintended percentage to 49.3 percent, although admittedly, the percentage is still much too high. All groups of women experience unintended pregnancy. A higher percentage of unintended pregnancies occur in women younger than 20 years of age, not married, Black, Medicaid eligible, and with less than 12 years of education. This measure will continue in next year's Annual Plan (Section IV).

Local health departments provided family planning services. There were 93 sites statewide. Last year 24 of those sites had extended hours or weekend hours to provide services for those who could not be seen during the routine hours of 8:30 to 5:00 PM. Many health departments began clinic integration efforts to better meet the needs of the family planning customers. Others have worked to keep a less than two week waiting time for appointments, prioritized services for teens and post partum women, and utilized outreach workers to follow up on missed appointments as well as to do case finding in local communities. The Family Planning waiver (reproductive health care services to all women under 185 percent of poverty) continues, and is presently being evaluated. Preliminary results are encouraging, in terms of the number of births averted, and the resulting cost savings.

5) **SIDS mortality rate (SPM #11).** In 1998, the SIDS mortality rate increased to 1.2 per 1,000 resident live births, from 0.9 in 1997. South Carolina did not meet its target of 0.8 for 1998. *Back to Sleep* program messages in collaboration with the March of Dimes and other partners were promoted during the last year. Additional focus on "Back to Sleep" education has also been emphasized with the Postpartum Newborn Home Visit. This measure will not be included in next year's Title V Annual Plan (Section IV), but will continue to be addressed through the DHEC Health Services Operational Plan.

CHILDREN

1) Percent of children through age 2 who have completed immunizations for Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, Hepatitis B.(FPM #5). South Carolina continued to

maintain a high level of immunization coverage with an estimated 89.0 percent of children through age two fully immunized. This accomplishment is slightly below our target of 90 percent, although the difference is not statistically significant. DHEC continued to work closely with its partners in the public and private sector.

2) The birth rate (per 1,000) for teenagers aged 15 through 17 years. (FPM #6). South Carolina's teenage birth rate improved in 1998 to 38.7 per 1,000 teens, a slight decrease from 1997. The 1998 target of 38 was almost met.

Health Department clinic services for this group has varied. All health departments offered family planning services during routine work hours. 24 of 90+ sites offered extended week day or weekend clinics to accommodate teens. Those areas of the state with institutions of higher learning partnered with the college's health services to deliver family planning services at the college or university. Teen pregnancy prevention programs in Catawba and Upper Savannah have numerous community-based efforts designed to delay sexual activities in teens.

- 3) Percent of third grade children who have received protective sealants on at least one permanent molar tooth. (FPM #7). South Carolina was not able to duplicate the 1998 survey of dentists for the 1999 reporting cycle, and continued to utilize the 1998 survey results applied to an updated population denominator of third graders. As a result, the state exceeded the 45 percent target for 1999, with 51.4 percent of 8-10 year olds reportedly with at least one sealant. This result was based on extrapolation from a survey of dentists in the state. See the Annual Plan (Section IV) for this measure for a description of the considerable ongoing and planned activities in oral health.
- 4) The rate of deaths to children aged 0-14 caused by motor vehicle crashes per 100,000 children. (FPM #8). NOTE: The definition for this measure has changed to include infants as well as children. The rate of deaths to infants and children aged 0-14 due to motor vehicle crashes was 7.4 per 100,000 infants/children in 1998 in South Carolina, which met the target of 7.4. The rate however, did increase slightly in 1998. DHEC provided child passenger safety education and free safety seats to prenatal and post-natal clients. Child passenger safety training was provided to community groups to increase the safe transport of children. Staff participated in safety seat check-ups and buckle-up events in the community which provided a forum to educate parents and demonstrate the correct use of safety seats and the need for seat belt use. Bicycle safety education was also provided to children and there parents, as well as free bicycle helmets.
- 5) Ratio of school nurses to the student population.(SPM #13). South Carolina did not improve in 1999, maintaining 28 of the 86 school districts with at least a 1:1000 nurse to student ratio. This continues to be a priority for South Carolina, but local school districts are autonomous, requiring gains to be made in a piecemeal manner. Local school districts continued to develop many partnership or collaborative agreements with entities outside the educational system, such as hospitals and health departments, to assure the availability of the school nursing component. Health Districts have pursued partnership relationships with school officials and teachers and this measure for the Annual Plan (Section IV) has been modified to more strongly reflect these collaboration and partnership efforts between schools and the

Health Districts (new SPM# 3).

- 6) STD infection rates in teens (15-19) in South Carolina. (SPM #14). The rate of Ct infections among 15-19 year olds in the state decreased slightly in 1998 from 2889 to 2726 cases per 100,000 teens. This result is slightly below the target of 2889. Given continued emphasis on case finding it is difficult to interpret the trends. Projected trends indicate that the quantified prevalence of the disease could increase as more cases are found. The "true" rate is still unknown. This measure will not be continued with the next Annual Plan (Section IV), but will be closely monitored through the DHEC Health Services Operational Plan.
- 7) The state has a childhood injury prevention program in place. (SPM #4). The target last year for 69 percent (9/13) of the districts having an injury reduction program in place was not reached, primarily due to a change in definition of this measure. To have a more specific indicator, two new variables were added to this measure: programs covering more than one MCH population and intentional injury prevention as required additional elements. With the new definition, only 6/13 districts reported having an injury prevention program in place. Injury prevention continues to be an agency priority given the magnitude of the problem (largest killer of children). Through the Injury and Disability Prevention Division, educational information was provided to the public regarding poisoning, drowning, fire safety and other injury causes. Fire safety educational materials were also provided to clients through the Post-Partum New Born Visit Program. Over 3,000 smoke alarms and 1,100 bicycle helmets were distributed statewide through all of the health districts. For the next Annual Plan (Section IV), this measure will continue using the new expanded definition.

Level 4: Infrastructure Building Services

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

- 1) Percent of Children with Special Health Care Needs (CSHCN) in the State CSHCN Program with a source of insurance for primary and specialty care. (FPM #11). South Carolina almost reached its 1999 target of 90 percent, with an estimated 89.4 percent of CSHCN in the CRS program having a source of insurance. The state did improve from 88.2 to the 89.4 percent figure. This was and continues to be a programmatic priority. With Medicaid expansion, this percentage should continue to increase over the next several years. See the description of activities under FPM #12 (percent of children without health insurance), under Infrastructure Building Services, Children, in the 2001 Annual Plan (Section IV).
- 2) The degree to which the State assures family participation in program and policy activities in the State CSHCN Program. (FPM #14). The target of achieving a score of "16" (on a 1-18 scale) was achieved. CSHCN family members are reimbursed for their participation and are serving on more task forces, even at the state level. Family members are also involved in in-service training of CSHCN staff and providers in a variety of ways.

3) The degree to which the State assures a transition is developed for those children aging out of the State CSHCN program. (SPM #5). South Carolina improved from a 9 to a 10 and met its target (on a scale of 1-12) this last year. A Transition work plan is in place which includes a parent education component. The State CSHCN program has established a statewide Transition Focus Group that is chaired by the Transition Coordinator. This focus group has developed criteria (the checklist) which addresses adult transition needs before exciting the CRS program. This criteria has been distributed, and training is available.

PREGNANT WOMEN AND INFANTS

- 1) **Percent of very low birth weight live births (FPM #15)**. 1.8 percent of all births in the state in 1998 were VLBW births, a slight decrease from 1997. This result met the target of 1.8. The VLBW trend in the state has not improved historically, but recent findings related to Bacterial Vaginosis and oral health, and their potential impact on prematurity, could present opportunities to the state. For the Annual Plan in 2001 (Section IV), research will continue and clinical interventions are planned (especially related to BV) in health department STD and FP clinics.
- 2) Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates. (FPM #17). For those VLBW infants whose birthweight and place of delivery were known, 69.8 percent of VLBWs were born in Level III facilities in South Carolina in 1998, a decrease from 1997 and below the 74 percent target set for the state, and substantially below the HP 2000 goal of 90 percent. South Carolina has been experiencing a steady decrease in the percentage of very low birth weight infants being delivered in Level III hospitals. Factors that partially explain this result include an increased number of Neonatologists practicing in the state and reimbursement systems which are not supportive of delivery in risk-appropriate setting. At the state level, public health is focusing on the issue and identifying strategies to increase the percent of VLBW births in Level III hospitals. See the Annual Plan for 2001 (Section IV) for further details.
- 3) Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester. (FPM #18). 82.6 percent of all births in 1998 were to women who began their prenatal care during the first trimester, a historic high. This percentage almost reached the target of 83.0 percent. There has been a gradual, yet consistent improvement in first trimester entry into care since 1989. This trend is seen among Whites as well as Blacks and Others. This is a multifaceted problem and requires work on several fronts, including accurate reporting on prenatal care entry on the birth certificates, physicians promoting the first visit during the first trimester and thirdly, information to women of childbearing age regarding the importance of early entry into care. See the 2001 Annual Plan (Section IV) for further details regarding interventions that are planned to improve the performance on this measure.
- 4) Percent of infants born to Black women who entered prenatal care beginning in the first trimester (SPM #10). 73.8 percent of resident Black women who gave birth in 1998 entered prenatal care in the first trimester in 1998. This percentage was far below the target of 83 percent set for the State overall, but substantially exceeded the specific target for Black women of 71 percent. Although the gap between Black and White women entering first trimester entry into

care has shown improvement for all segments of the population over the last several years, the differences are still substantial. South Carolina is doing a better job of addressing systems issues such as access to care, partnerships for care, and outreach. Thirty-six of the 46 county health departments had partnerships with private providers for prenatal care. This allowed the client choice, as well as flexibility for care. The staff work closely with their partners to provide Family Support Services and WIC to enhance the clients ability to have a safe and healthy pregnancy. In those counties still providing prenatal care, systems of access were monitored regularly to identify barriers. This measure will not be included in the 2001 Annual Plan, but will be included and monitored closely in the DHEC Health Services Operational Plan.

CHILDREN

- 1) **Percent of children without health insurance**. (**FPM #12**). Based on CPS estimates of uninsured in the under 200 percent of poverty population, 13.5 percent of children were uninsured in the state in 1996-1998, a slight increase from the 1995-1997 estimate. The target for both 1999 and 2000 is 13 percent. Districts have been working very hard to increase outreach and enrollment into the Medicaid and SCHIP programs.
- 2) Percent of potentially Medicaid eligible children who have received a service paid by the Medicaid Program. (FPM #13). South Carolina is placing tremendous effort on increasing Medicaid enrollment and linking these enrolled children to primary care services. Based on 1999 population estimates, and using the latest HCFA available 2082 report, the number of children potentially eligible for a Medicaid service who received a service in 1999 was 87.5 percent. All 13 health districts continue to emphasize private/public partnerships for medical homes for children. In 1993, efforts began with four model partnerships. Currently there are over 100 partnerships for medical homes for children in 36 of 46 counties. Even with the increasing number of partnerships, there is still a need to continue to provide comprehensive well child care in our county health departments. All 13 health districts still provide EPSDT services, as well as some services to uninsured clients.
- 3) The rate (per 100,000) of suicide deaths among youths 15-19. (FPM #16). The suicide rate among youth 15-19 in South Carolina in 1998 was 8.3 per 100,000 youth, an increase from the 6.1 rate in 1997. South Carolina did, however, meet the 1998 target of 9.3 per 100,000 youth. Historically the rate has been unstable, making projections difficult. Districts developed activities, primarily in partnership with schools and the local county mental health centers during 1998.
- 4) Percent of public health districts with at least one county that has a process which assesses health status, identified resources and gaps in health services, plans based on the assessment, and implements activities to reach specific goals. (SPM #15). 31 of the 46 counties (67 percent) reported at least an initial activity in all eight areas of the check-off sheet (see below):
- Ongoing Needs Assessment (completed and updated annually, includes needs, assets and resources) (30/46 counties reported activity);

- 2. Inventory of Community Groups (32/46 counties reporting activity);
- 3. Analysis of MCH Indicators: (33/46 counties);
- 4. Identification of gaps in services and systems: (32/46 counties);
- 5. Identified, broad-based process to prioritize needs: (29/46 counties);
- 6. Solutions identified: (30/46 counties);
- 7. Overall plan established: (27/46 counties);
- 8. Community is involved with all phases of process (not until next year's Annual Report section).

17 counties have an active FIMR group and six counties have started Child Health and Safety Councils to begin to look at child deaths. In addition, 22 counties and three cities have participated in Healthy Communities training. This measure will not be included in the 2001 Annual Plan, but will be addressed through the DHEC Health Services Operational Plan.

2.5 Progress on Outcome Measures

1998 brought little change or improvement in the Outcome Measures that the state is tracking. Among the six measures, improvement was seen only in the Perinatal Mortality Rate. In 1998 the Perinatal Mortality Rate was 15.0, a 6.0 percent improvement from 1997, although still above the 1996 rate of 14.7. Negative trends were seen in the Neonatal, Postneonatal and Child Mortality Rates. The Neonatal Mortality Rate increased 1.5 percent from 6.7 to 6.8 per 1,000 live births in 1998; the Postneonatal Mortality Rate increased 3.7 percent, from 2.7 to 2.8 per 1,000 live births; and the Child Mortality Rate increased 5.4 percent from 27.6 to 29.1 per 100,000 children. Targets in 1998 for Neonatal and Postneonatal Mortality were not met. Despite the increase in the Child Mortality Rate its target was met, as historically this last increase did not undue the steady downward progress made on the rate over the last several years. Although the State has been making steady improvement in all of the Outcome Measures over the past 20 years, these most recent upward trends are troublesome. For Infant Mortality and the Black to White Infant Mortality ratio, they did not change in 1998, compared to 1997: 9.5 per 1,000 live births and 2.4 respectively for both years. The Infant Mortality Rate reached its historical low in 1996, then spiked in 1997, and now has remained unchanged for a second year. Over the past six years the Black to White Infant Mortality Ratio has not gone below 2.0. This disparity largely explains the reason why the overall infant mortality rate of the state is much higher than the national average, as South Carolina has a higher proportion of Black infants than the nation as a whole.

Despite these more recent negative results, South Carolina has made steady improvement in all of the Outcome Measures over the past 20 years as indicated. There are many contributing factors and determinants that have an impact on these outcome measures, and South Carolina is maintaining high levels of effort and making steady progress on several of the performance measures that can affect positively all of these Outcome Measures. For Perinatal, Neonatal, Postneonatal and Infant Mortality, these performance measures include: SIDS mortality, newborn metabolic screening, breastfeeding, new born hearing screening, insurance coverage and medical homes for CSHCN, first trimester entry into care for all races, and for African American women specifically, community assessment and planning, and births to

teens. For the Child Mortality Rate, immunizations for two year olds, MVA attributable deaths, expansion of childhood injury reduction programs, and overall uninsured percentages among children have all improved or been maintained at a high level. Due to these overall historic positive trends in many of the performance measures, it is our hope that the historical downward trends in the outcome measures will continue over time.

A major issue facing the nation, and South Carolina in particular are the racial disparities seen in the Outcome Measures. All major Mortality Rates for Blacks continue to be substantially higher than for Whites. The ratio between the Black and White IMR Outcome Measure is affected by the percentage of VLBWs, pregnancy intendedness, first trimester entry by race, and births to teens by race performance measures, among others. Despite there not being a racial disparity in the percentage of VLBWs being delivered in Level III facilities, the overall downward trend the State is experiencing affects Black infants more, given the disproportionate share of LBW infants born to Black women. The Title V program in the state in 2000 and 2001 will be focusing more attention on these outcome measures and working to ensure that the best strategies we have at our disposal are being utilized.

Factors outside the scope of the Title V program that impact these outcome measures include historical differences in socio-economic status and educational opportunities between Blacks and Whites in South Carolina.

See Supporting Documentation SD 12 CORE (1991-1995).1 through SD 12 CORE (2001-2005).2, (5.8), in the Supporting Documents Section, for a 5 year projection with year-to-year goals for each outcome measure.

III. REQUIREMENTS FOR THE APPLICATION [Section 505]

3.1 Needs Assessment of the Maternal and Child Health Population

3.1.1 Needs Assessment Process

The Maternal and Child Health (MCH) Epidemiology Division in the Health Services Bureau of Epidemiology is responsible for development and maintenance of an efficient MCH surveillance system. The goal is to afford timely and accurate data with the capacity of vital comparisons among significant racial and ethnic subgroups, geographic areas, and health service providers. The MCH Epidemiology Division has primary responsibility for completing needs assessments required under the federal Title V (MCH Block Grant) program in South Carolina. **Table 3.1.1a**, below contains an overview of the plan for completing the current required 5-Year Comprehensive Needs Assessment.

Table 3.1.1a Overview of Needs Assessment Process

Phase 1: Preparation

Phase 2: Work Group Process

Phase 3: Setting State MCH Priorities
Phase 4: Development of State Report

Phase 1 of the needs assessment process constituted the preparatory steps taken by the MCH Epidemiology Division in collaboration with the MCH Bureau. Preparation included determination of the committee structure most appropriate as well as identification and collection of data deemed potentially useful to the subcommittees in carrying out the actual assessment.

The acting MCH Bureau Director (Linda Price), the MCH Epidemiology Division Director (Donna Rickert), and the MCH senior planner (Joe Kyle) consulted with top MCH program managers in setting the role and composition of the Oversight/Steering Committee. This committee provided leadership and direction regarding both the overall process and the subcommittee process. MCH program managers were consulted in the determination of a functional subcommittee structure along with the purpose and staffing of each committee. Five population specific subcommittees were defined (Table 3.1.1b), along with expert leadership and expert staff to participate on each. In addition, a staff member from MCH Epidemiology was assigned to serve as co-leader for each of the five subcommittees.

The expert opinions of our highly trained and seasoned MCH Central Office and District Office program staff have long been an important contribution in the MCH assessment and planning process. Expert subcommittee leaders

Table 3.1.1b: Five Population Specific Subcommittees

- 1. Pregnant Women and Infants (Leader: Burnese Walker-Dix, (WIC Program Director), and Epidemiology Co-Leader: Dr. Patsy Myers)
- 2. Children Ages 1-9 (Leader: Angela Olawsky, (WCS Nurse Consultant), and Epidemiology Co-Leader: Herman Core)
- 3. Adolescents Ages 10-19 (Leader: Sandra Jeter, (Social Worker Asst. Director), and Epidemiology Co-Leader: Herman Core)
- 4. Reproductive Age Women Ages 14-44 (Leader: Kahlil Demonbreun, (WCS Nurse Consultant), and Epidemiology Co-Leader: Herman Core)
- 5. Children With Special Health Care Needs (Leader: Linda Price, (CSHCN Director and acting MCH Bureau Director), and Epidemiology Co-Leaders: Dr. Donna Rickert, Khosrow Heidari).

were charged with facilitating the process to determine top priorities (7-10) and specific recommendations that would address identified priorities. The summary of the recommendations and conclusions are included in this needs

assessment section. For detailed reports from each population sub-committee, please see Appendix G.

To assist subcommittees to this end, MCH Epidemiology Division staff prepared specific data analyses and informational reports each work group might need and/or find useful in both determining priorities and making recommendations. Subcommittees were encouraged to request additional data and/or informational reports as the need became apparent. A few illustrations of the types of analyses and reports prepared for the subcommittees can be found in **Table 3.1.1c** below.

Table 3.1.1c Illustration of Data and Informational Reports

- 1. Title V Federal and State Performance Measures
- 2. Vital Data, SC DHEC
- 3. SC Teen Pregnancy Data Book
- 4. Region IV Network for Data Management and Utilization Data
- 5. Family Planning Program Data
- 6. Temporary Assistance for Needy Families (TANF) Data
- 7. SC MCH Data Book
- 8. SC Youth Risk Behavior Survey
- 9. SC Pregnancy Risk Assessment Data (PRAMS)
- 10. National PRAMS Data

Phase 2 of the assessment process is reflected in the work of the five population specific subcommittees. The subcommittees were charged with assessing the major health needs of their specific population and prioritization of recommendations to address identified needs. The subcommittees used a brainstorming process to come up with a list of problems specific to their population based on their experiences and perceptions. The exhaustive list of perceived problems was then refined by merging similar problems through a nominal group process. Data and informational reports provided by MCH Epidemiology were used to help the group with not only problem identification, but to help validate or nullify a perceived major problem. The final list of merged and clarified problems was transformed into specific recommendations for each problem by levels of the pyramid. This open but structured group process enabled the five population specific subcommittees to quickly develop a very general understanding and agreement on the major health issues and a list of health needs for each specific target population.

The mainstay of the data analysis by the population specific subcommittees involved vital records data for select MCH health status indicators along with key program level data. The goal of these assessments was to review interpretative analysis for both the state and local (district/county) level data to establish a pattern of improvement, worsening, or no change in performance. A second component of the assessment was determination of the extent of disparity among the state's population subgroups. Thirdly, a comparison was made regarding the state's total population and population subgroups with the US Healthy People Year 2000 objectives for the nation.

A "Leaders Group" was formed, in-process, which included the leaders and co-leaders of each of the five population specific subcommittees. Individuals listed in the previous **Table 3.1.1b**, represent the composition of this group. This group was born out of each subcommittee leaders' requesting to share and discuss cross-cutting issues and concerns as well as lessons learned within their subcommittee. Moreover, meetings of this group also provided a forum for ongoing review and clarification of the subcommittee process. Formation of this group decreased the need for frequent meetings and coordination by the Oversight/Steering Committee. Electronic mail was used as the primary mode for ongoing communication with members of the Oversight/Steering Committee. This decision accommodated both the importance of frequent updates and the ongoing important contributions coming from District Office staff and community partners.

Data Limitations

Limitations were largely recognized during Phase 2. The time allotted for completing the subcommittee process was tight, particularly given other competing MCH priorities. The existence of more interpretative trend analyses for common data would have been very helpful.

The Women, Infants, and Children's (WIC) program has limited ability to prioritize data requests partly due to a constant high demand for a long line of program reports. Also, the capacity of the DOS-based Patient Automated Tracking System (PATS) is reportedly limited. Consequently, obtaining both timely and accurate data remains a problem.

Registry and program data are not linked well enough to define a strong information infrastructure. Also, our somewhat limited access to current census data limits our ability to produce specialized age and race specific rate calculations. The strong partnership with the Office of Research and Statistics (ORS) within the State Budget and Control Board has helped reduce this constraint.

The upcoming State Systems Development Initiative (SSDI) grant activities and availability of an internet-based MCH data system will be very helpful in resolving several limitations. The result will be increased capacity to access information needed to carry out ongoing assessment, surveillance, and evaluation activities. This progress will also enable us to move towards a more comprehensive surveillance system with the production of much needed standardized reports in support of program activities and policy development.

Data to Action Process

Development of the state performance measures for the year 2001 represents **Phase 3** of the overall needs assessment. Development of the Year 2001 state performance measures benefitted directly from the work of the five population specific subcommittees. Similar to past efforts, a consultative process involving key MCH staff was used to determine priorities and state performance measures.

At the April, 2000 MCH Team meeting, the 5-year needs assessment subcommittees presented their summary findings along with recommendations for their specific population. Through an open but structured decision-making process, the 10 state draft priorities were determined out of the information presented. Subsequent MCH Bureau discussions finalized the priorities. With the priority listing, MCH Bureau staff then took the state priorities and, in coordination with the various programs, developed the state performance measures. The "Core" performance measures were also reviewed carefully to ensure that the State measures were complementary and developed to fill in gaps that the Core measures did not address.

Collaboration

Finally, **Phase 4** of the overall needs assessment process involved the synthesis of work of all subcommittees into a single state needs assessment report, in accordance with the guidance, by the MCH Epidemiology Division.

The Title V comprehensive needs assessment requirement has provided yet another opportunity for further enhancement of cross-program and interagency sharing data needs, concerns, and plans. Additionally, this process provided the opportunity for data managers in other state agencies to express their current data needs and plans, and how our agency might be more helpful in their efforts. Although our alliance has been positive and longstanding with other state agencies, the data demands of the needs assessment further enhanced relationships with some. State agencies such the Department of Social Services, the Department of Health and Human Services, and the State Budget and Control Board were particularly helpful throughout the process.

DHEC Health Services program staff and MCH Epidemiology staff worked cooperatively throughout the process. This occurred largely within established committees, but also outside committees to assure a smooth process and a clear understanding of the data.

Collaboration with important community advocates including South Carolina March of Dimes, the three Healthy Start Initiatives, and the School of Public Health at the University of South Carolina was provided for largely by their direct involvement on committees and/or analysis of select data sources.

Collaboration with local Health Department staff occurred by way of the requirement that they describe the local health care delivery system. Each of the States thirteen (13) Public Health Districts submitted a description of characteristics of their health care delivery system that impacts the MCH population. This provided vital information in the overall assessment and determination of the States priority needs and yet another opportunity to assure that the perceptions of local staff were represented in the outcome of the needs assessment.

District representation on the population specific subcommittees provided for the ongoing sharing of information between District Office staff and Central Office staff. Additionally, this assured ongoing district update regarding subcommittee activity as well as that district concerns and perspectives were brought to the table.

A special session was conducted at the annual Epidemiology Conference (April, 2000) to provide yet another opportunity for attending district and county MCH staff to have input into the assessment process. The agenda included a presentation of the progress made by each of the five population specific subcommittees and the opportunity for open discussion and input by all in attendance. Again, the target of this prearranged session was district staff.

Sources Used and Strengths and Weaknesses of Methods

A significant weakness in the process involved having to make numerous contacts to get data. There is no single centralized point to obtain data. However, ongoing efforts including our partnership with the State Budget and Control Board along with internal efforts within our Bureau of Epidemiology (e.g., formation of the Epidemiology Technical Support Unit) will bring about much improvement in creating a single point for data or a data warehouse.

One of the strengths of the process was the collaboration effort. Membership on the sub-committees was drawn from Central Office MCH staff, Bureau of Epidemiology staff, and staff from Biostatistics, including the PRAMS Coordinator. Other committee members included representatives form the Public Health Districts, and community organizations such as March of Dimes and Healthy Start. Input from the community and clients served came in the form of responses to surveys and results from focus group discussions. This gave the committees a wide variety of backgrounds and perspectives to draw from.

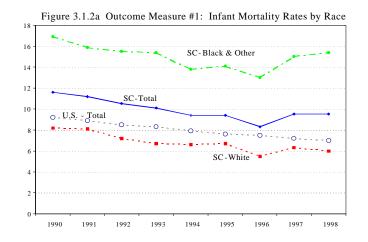
Another strength of the process was the brainstorming method used by the committees at the beginning of the project. This allowed unlimited input by all committee members to get a complete picture of the health needs of their given population. The results of this session were then refined and consolidated into broader issues from which the recommendations were drawn.

The use of electronic mail as a primary mode of communication facilitated increased input from Committee Members and enabled frequent updates and short response times.

3.1.2 Needs Assessment Content

3.1.2.1 Overview of the Maternal and Child Health Population's Health Status

The following describe the health status of the State MCH population, broken down into the three main sub-populations of (1) pregnant women and infants; (2) children; and (3) children with special health care needs. The Healthy People 2000 Objectives related to these populations provide a structure for this description, as do the Title V Federal Performance and Outcome Measures.



Population Group 1: Pregnant Women and Infants.

Infant Mortality

South Carolina has experienced significant improvements in infant mortality through the 1990s. From a high of 11.6 deaths per 1,000 live births in 1990, the total infant mortality rate reached its lowest point in the decade in 1996; the rate of 8.3 represented a 29% decrease in that six-year span. In 1997, the

total rate increased to 9.5 and remained at that level in 1998 causing an upward shift in the mortality trend. Given this pattern, the decrease in infant mortality from 1990 to 1998 was 18% for all races combined and although clear progress is being made, unless the rates improve in the next two years we will fall short of attaining the Year 2000

Objective of no more than 7.0 infant deaths per 1,000 live births. Trends in infant mortality rates from 1990 through 1998 are shown in Figure 3.2.1a.

Race-specific infant mortality rates have also improved through the decade of the 1990s, though not at the same rate. Both white and black and other rates reached an all-time low in 1996, as the chart shows. The white rate that year of 5.8 represented attainment of the Year 2000 Objective, but the black and other rate, though it had decreased by 20% since 1990, was 12.9 and was not yet at the

Figure 3.1.2b South Carolina Outcome Measure #2: The Disparity Between the Black and White Infant Mortality Rate*

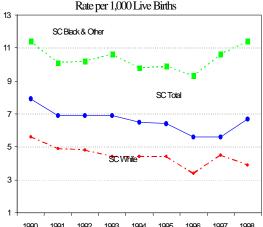


Year 2000 target rate of 11.0 set for black infants. The black and other rate was approximately 2.1 times higher than the white rate at the beginning of the decade, but by 1998 it was 2.5 times higher. Racial disparities in infant mortality rates are shown as the ratio of black to white infant deaths in Figure 3.1.2b depicting Title V Outcome Measure 2.

Neonatal Mortality

Most of the difficulty in accomplishing further reductions over the past several years in infant mortality can be attributed to persistence in the neonatal mortality rates. The black and other rate in particular remained unchanged through the first half of the decade, varying only slightly around an average of 10.3 deaths per 1,000

Figure 3.2.1c Outcome Measure #3: The Neonatal Mortality Rate per 1,000 Live Births



live births. By 1998, this rate had increased to 11.4, showing little likelihood of reaching the Year 2000 target

of 7.0 for black infants. By contrast, the white neonatal mortality rate improved over the decade from a high of 5.6 in 1990 to a low of 3.9 in 1998. This 30% reduction over the 8-year period enabled South Carolina to be successful in attaining the Year 2000 Objective of 4.5 neonatal deaths for white infants. Reducing racial disparities in neonatal deaths appears to be the

key to reducing the statewide infant mortality rate: in 1990, black and other infants had 2.0 times the risk of death as white infants, but by 1998, this risk had increased to 2.9.

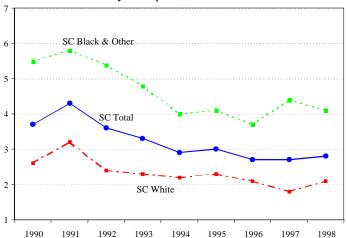
Figure 3.1.2c depicts the trends in neonatal mortality rates over the decade of the 1990s, and illustrates the impact of racial disparities on the total statewide rates.

With respect to underlying causes of neonatal deaths, racial differences provide important clues about where to focus prevention efforts. Deaths associated with adverse maternal conditions (e.g., maternal complications or pregnancy, pre-existing maternal health conditions, complications of pregnancy, labor, and delivery) increased significantly for black and other infants, but not so for white infants. In addition, increased deaths associated with congenital anomalies, though relatively small in number, are noteworthy among black and other infants for the time period 1995 through 1998. Finally, deaths associated with very low birth weight and prematurity show clear racial differences. Some infants who are born at very low birth weights die from specific causes that are not directly attributable to prematurity and low birth weight per se. Deaths due to injuries or to fatal congenital anomalies provide representative examples. When deaths of very low birthweight infants that are directly attributable to causes unrelated to prematurity are excluded, we see substantial improvements in very low birthweight death rates for both races across the decade. However, the rates for black and other infants are consistently higher than those for whites and the disparities have become more pronounced. In 1990, black and other infants were 2.7 times more likely than white infants to die from conditions associated with very low birth weight and prematurity; by 1998, this black/white ratio had increased to 3.4.

Post Neonatal Mortality

Significant improvements in South Carolina's postneonatal mortality rate occurred during the 1990s. The maximum difference in the rate for black and other infants occurred between 1991 and 1996, with the rate for 1996 being 66% lower than that for 1991. The maximum difference in rates for white infants occurred between 1991 and 1997, where the 1997 rate was 44% lower than that for 1991. For all races combined, the rate decreased by 35% over the time period 1990 - 1998. Although sharper decreases have occurred for the black and other rate, racial disparities are still present. The disparity was greatest in 1997 at 2.4, and at its least in 1996 at 1.8.

Fig. 3.1.2 d Outcome Measure #4: The Postneonatal Mortality Rate per 1,000 Live Births



Much of the improvement in

postneonatal mortality in South Carolina can be attributed to significant reductions in deaths due to Sudden Infant Death Syndrome (SIDS). The declining mortality rate was most pronounced for black and other infants, and

Figure 3.1.2 e Trends in the South Carolina Resident Fetal Mortality Rates by Race, 1990 - 1998 18 12 White 1991 1998

coincided in time with our public health educational "Back to Sleep" initiative in which mothers were advised that putting infants to sleep on their backs has been shown to reduce the risk of SIDS. Trends in postneonatal mortality rates from 1990 through 1998 are shown in Figure 3.1.2d as Title V Outcome Measure 4.

Fetal Mortality

Fetal mortality rates for all races combined have remained unchanged through the decade of

the 1990s, with an average of 10.3 fetal deaths per 1,000 live births plus fetal deaths each year. The white fetal mortality rate showed a statistically significant rate decrease of 24% from 1990, in which the rate was 7.5, to 1998, when the rate dropped to 5.7. This brings the white fetal mortality rate close to the Year 2000 target of no more than 5 fetal deaths per 1,000 live births plus fetal deaths. The rate for black and other infants showed no statistically reliable changes, and the rates for the first half of the decade were actually lower than those for the second half. The 1998 rate of 15.6 was twice as high as the Year 2000 fetal death rate of no more than 7.5 for blacks. Figure 3.1.2e shows trends in these rates by race through the 1990s.

Low Birth Weight and Very Low Birth Weight

The overall proportion of infants born at low and very low birth weights, regardless of their survival outcomes, provides another measure against which to evaluate infant health status. South Carolina has experienced a slightly increasing trend in low weight birth rates over the past several years. In 1992, 9.0% of all live births weighed less than 2500 grams and by 1998 the percentage had increased to 9.6%. The increasing trend was similar for singleton live births, with 7.8% born below the low birth weight criterion in 1992 and 8.0% in 1998. The Year 2000 Objective identifies an overall low birth weight target of no more than 5% of live births. Our current trend does not appear to be approaching this goal. Reduction of racial disparities in low birth weight represents a clear need; the black and other rate has remained twice that of the white rate consistently through the 1990s.

A trend that parallels the one for low weight births can be observed for infants born at very low weights. In 1992, 1.8% of all live births and 1.5% of all live singleton births weighed less than 1500 grams at birth. By 1998, 1.8% of all live births and 1.6% of all live singleton births were born in this weight category. Although we are close to attaining the Year 2000 Objective of no more than 1% of infants born at very low weights, we will need to see improvements beyond the trends observable now if we are to actually reach this goal. Reducing racial disparities in very low birth weight should contribute substantially to this end. The rate for black and other infants has consistently been 2.5 times that of the white rate through the 1990s, and has shown a slight tendency toward an even greater disparity in 1997 and 1998.

Particularly noteworthy is the increasing proportion in recent years of live born infants weighing less than 500 grams. Because less than 1% of infants born in this extremely low weight range survive the early neonatal period, such births have been seen as essentially non-viable. This increasing proportion of extremely low weight births, seen nationwide as well as in South Carolina, most likely represents a shift in physicians' perception of viability resulting from increasingly sophisticated technologies for providing life support to these most fragile of all infants.

Prenatal and Risk-Appropriate Care

Efforts to prevent the likelihood of pre-term very low-weight births relate to promoting early, risk appropriate prenatal care. South Carolina is making good progress toward the Year 2000 goal of increasing to at least 90% the proportion of all pregnant women who receive prenatal care in the first trimester. In 1998, 82.6% of all new mothers received prenatal care in the first trimester. In that year, 86% of all white mothers and 73.8% of all black and others mothers had early care.

These percentages fall short of the Year 2000 target of 90%, but the white rate is close, and the rate for black

mothers improved by 29% in the short 6-year span from 1992 to 1998. Consensus exists among public and private sector health care providers that there is a maldistribution of providers in rural areas. There are problems associated with the concentration of obstetrical providers in the urban areas that leave shortages in the rural areas, with large segments of the childbearing population without adequate transportation, and with the supply of perinatal providers falling far short of the demand for their services.

Risk appropriate care is indexed in the Title V Federal Performance Measures as the percent of very low weight infants delivered at facilities for high-risk deliveries of neonates. Analyses of South Carolina's regionalized model of service delivery for high risk pregnancies have demonstrated its efficacy in providing tertiary-level care to prevent infant deaths. However, the percent of very low weight infants delivered at tertiary-level hospitals has decreased from 76% in 1992 to 69.8% in 1998. This decrease is associated with competition among hospitals for the management of more complex deliveries. As a result, South Carolina has made little progress in recent years in attaining the Year 2000 Objective of increasing to at least 90% the proportion of women and infants who receive risk-appropriate care.

Adolescent Pregnancy

The fertility rate for South Carolina adolescents ages 14 - 17 has followed the national decreasing trend. Whereas in 1992 the rate for all races combined was 34.6 live births per 1,000 female population ages 14 - 17, by 1998 it had dropped to a rate of 31.1.

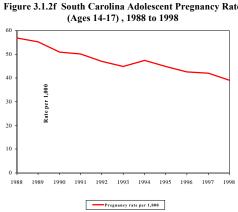
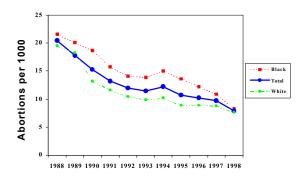


Figure 3.1.2f South Carolina Adolescent Pregnancy Rate

See graphs 3.1.2f above and 3.1.2g below.

The fertility rate measure is calculated for live births Adolescent pregnancy rates, by contrast, only. include live births, fetal deaths, and pregnancy terminations. Although ascertainment of pregnancy terminations is less complete than that for live births and fetal deaths, this composite measure provides in many ways a more useful index of reproductive health among adolescents than does the fertility rate. The pregnancy rate for adolescents aged 14 - 17, like the fertility rate, has decreased through the decade of the 1990s. By 1998, the rate for all races was 39.1

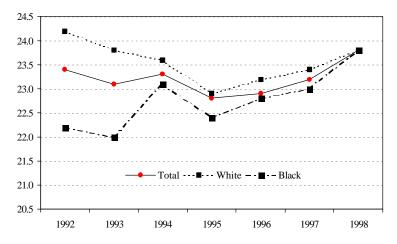
Figure 3.1.2g South Carolina Adolescent Abortion Rates, By Race 1988 to 1998

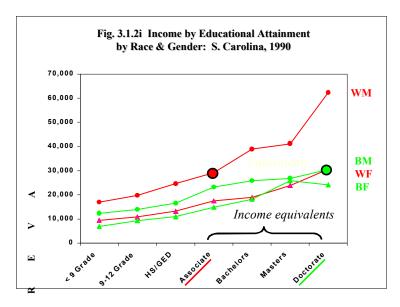


C-Sections

C-section deliveries dropped from 1992 to 1995 but have been on the upswing since then. The race gap for C-sections is closing. In 1992, 22% of deliveries to black and other women versus 25% for white women for C-sections. In 1998, these was virtually no difference. (Graph 3.1.2h)

Figure 3.1.2h South Carolina Cesarean section delivery rate





Lifestyle Issues

Income is a significant factor in quality of life for women. It impacts access to health care, food security, and a host of other lifestyle issues. Figure 3.1.2i shows income by educational attainment by race and gender. Both black and white females make significantly less than white males at all educational levels, and have comparable incomes to black males. A large proportion of women are low income or poor, based on federal

poverty guidelines, and many head single-parent households. Figure 3.1.2j shows the proportion of all racial and ethnic groups in South Carolina who are low-income or poor by federal poverty standards. Since women comprise at least half of all these population groups, a significant proportion of women in the State are low-income or poor. One of the greatest impacts of income on women is in access to health insurance.

	PERCENT POOR (<fpl)< th=""><th>PERCENT LOW-INCOME (<200% FPL)</th></fpl)<>	PERCENT LOW-INCOME (<200% FPL)
White, Non-Hispanic	10	26
Asian/Pacific Islander ALL RACES/ETHNICITIES	14 15	29 33
Black, Non-Hispanic	27	49
Hispanic, All Races	30	61
Native Amer/Aleut Eskimo	31	54

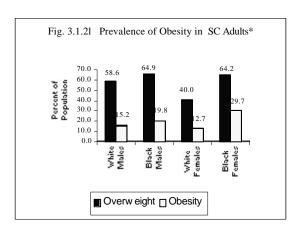
Fig. 3.1.2.k Health Insurance Coverage Of Low-Income Nonelderly Adults; By Race And Ethnicity, 1997*

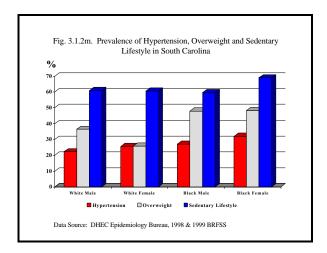
	F	PERCENT				
	Uninsured	Publicly Insured	Privately Insured			
Black, Non-Hisp	34.1	29.2	36.7			
White, Non-Hisp	31.5	18.3	50.2			
Asian/Pacific Is	38.9	14.3	46.8			
ALL RACES/ETH	36.9	19.8	43.4			
Hisp, All Races	52.6	16.5	30.9			
Native Amer/Esk	57.3	28.8	13.9			

^{*}Source: Urban Institute calculations from the 1997 National Survey of America's Families.

Figure 3.1.2k shows results for South Carolina of the 1997 National Survey of America's Families. This survey showed that more than one-third of all South Carolina adults were without any type of insurance coverage, public or private. While these results are not broken down by gender, one can extrapolate that approximately the same proportion of women are without any type of health insurance.

Nutrition is a critical health issue for South Carolina's women. Nutritional status can significantly affect pregnancy outcomes either positively or negatively. Figure 3.1.2l shows the prevalence rates for South Carolina adults by race and gender from the Behavior Risk Factor Surveillance System (BRFSS), for 1993-98. More than 60% of black women are overweight and 30% are reported to be obese. For white females the proportions are somewhat smaller, but still high.



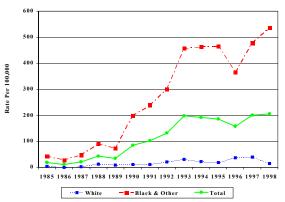


The results of the BRFSS (Figure 3.1.2m) for sedentary lifestyles and hypertension showed similar results. Almost 70% of black females were reported to have a sedentary lifestyle, and 60% of white females. The prevalence of hypertension in black women is about 32%, and for white women the prevalence is 25.5%. This can have serious consequences for pregnancy outcomes.

Another serious health issue for women of childbearing age is STDs. HIV infections have increased significantly for women in South Carolina, from 8.3 per 100,000 in 1988 to 20.4 per 100,000 in 1997. This is almost a three-fold increase. About one-third of all HIV cases are women, and of those, about 83% occur in black women. The prevalence rate for white women is 4.5 per 100,000, and for black females is 51.0 per 100,000, more than a tenfold disparity. Chlamydia is a significant problem in South Carolina. The prevalence rate in 1998 was 484.3/100,000, a significant increase in one year from 1997's rate of 331.3/100,000. South Carolina has the third highest chlamydia rate in the nation. Only New York and Delaware have higher chlamydia rates.

Figure 3.1.2n shows the incidence rate of babies born to women with HIV or HIV Risk status. This group entails

Figure 3.1.2n Incidence Rates of Babies Born to Women with HIV/HIV Risk By Race and Year (1985-1998)



women who are either HIV positive, injecting drug users, blood transfusion recipients or who had sex with the following: an injecting drug user, bisexual male, transfusion recipient or HIV positive individual. The majority of the women are HIV positive. Once again we observe a significant disparity in incidence rates by race, with the rate for black and other babies born to mothers with HIV/HIV risk being much greater than that for whites. Incidence rates for white babies varied between a low 3.1 per 100,000 in 1987 and a high 39.4 per 100,000 in 1997 whilst those for black and other babies varied

between 29.2 per 100,000 and 536.5 per 100,000. The incidence rate for white babies increased between the period 1985 to 1993 and began to decrease in 1994 and 1995, it peaked in 1997 at 39.4 per 100,000. The rate for black and other babies showed a steady increase over the period 1985 to 1998 with the only decrease occurring in 1996, the rate peaked in 1998 at 536.5 per 100,000. When we examine the rate for all races combined we observe a steady increase between 1985 and 1998 with the only decrease occurring in 1996, the highest rate occurs in 1998 at 206.2. The racial disparity in rates for babies born to women with HIV/HIV risk is most likely a consequence of the disparity in HIV incidence and prevalence rates for black and other versus white women.

Population Group 2: Children

South Carolina has approximately 1.34 million children and young adults between the ages of 0 and 24. By 1998 Census estimates, 62% of them are white, 36% are Black, 1% are Asian, and less than 1% are of other races. Of the total population for this age group, 2% are Hispanic.

Table 3.1.2a below describes the South Carolina population of children and young adults aged 0 through 20 in terms of age group and standing with respect to federal poverty levels.

Table 3.1.2a South Carolina Population Distribution of Children ages 0-24 Years by Race and Age
Group

Age Group	Total	Wh	ite	Black		Black Other		er
		Number	Percent	Number	Percent	Number	Percent	
<5 years	256,000	158,000	61.7%	95,000	37.1%	3,000	1.2%	
5-14 Years	510,000	308,000	60.4%	195,000	38.2%	7,000	1.4%	
15-24 Years	561,000	364,000	64.9%	188,000	33.5%	9,000	1.6%	
Total	1,327,000	830,000	62.5%	478,000	36.0%	19,000	1.4%	

Geography

Children under age 5 comprise about 7.4% of the total population of the state. Children ages 5-17 comprise 19% of the population. Geographical distribution of children less than 5 years of age in the state ranges from 5.2% to 9.8% of total population for a county, with McCormick County having the lowest percent and Berkeley County having the highest. The highest number of preschool children is found in Charleston County with just over 26,600 preschoolers, and the smallest number found in McCormick County with just under 500.

School age children comprise from 16% to 24% of the total county populations, with Beaufort County having the smallest proportion and Williamsburg County having the largest proportion. The largest number of school-age children is found in Greenville County.

Household make-up

As of the 1990 census, 25% of all children lived in single-parent households, including 14% white children and 44.5% of Black children. Almost one out of four children under 6 live in single-family households. Black children under 6 were four times as likely to live in single-parent households than white children under age 6. Single parent households more often than not are living in poverty. More than 50% of children living in single-parent households were poor, while only about 6% of children in 2-parent households lived in poverty. Some of the population less than 25 years may themselves be the heads of households with or without children.

Povertv

Poverty is a significant risk factor for poor health outcomes in children. Poverty is often the underlying cause of poor health due to poor access to health care, poor nutritional status and often substandard and unhealthy housing. Table 3.1.2b below describes the population of children and young adults aged 0 through 20 in terms of age group and standing with respect to federal poverty levels.

Table 3.1.2b South Carolina resident children and young adults by age group and poverty status using (1998 Federal Poverty Guidelines) as of July 1, 2000

Age	Total Population	Below 50%	51-100% of	101-125% of	126-133% of	134-150% of
Group		of Poverty	Poverty	Poverty	Poverty	Poverty
0	51,300	5,953	11,450	15,217	16,108	18,209
1-5	258,500	29,909	58,678	75,460	80,466	92,390
6-14	484,700	45,589	95,998	126,579	134,997	155,392
15-18	226,600	18,499	39,975	53,153	56,698	65,951
19-20	108,600	8,604	16,452	20,710	22,110	25,630

Figure 3.1.20 shows a graphical representation of the same information indicating a much higher proportion of African American children living in poverty than white children.

Figure 3.1.20 Percent of Children age 18 or less Living in Poverty

Mortality

Tables 3.1.2c through 3.1.2g below show the top ten leading causes of death by age and race, for all of South Carolina's children and young adults ages 1-24 years. Accidents are the leading causes of death in all age groups. By far the most common type of fatal accidents is motor vehicle crashes.

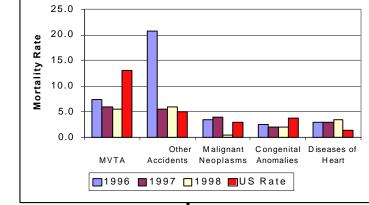
In children ages 1-4 (Table 3.1.2c), infectious diseases are the second most common cause of death. Diseases of the heart and homicide are also among the top ten leading causes of death in 1-4 year olds. Diseases of the heart, malignant neoplasms, and congenital anomalies are more common causes of death in white preschoolers than in black and other

preschoolers. Homicide is four times more common in black preschoolers, than white preschoolers as a cause of death. In this age group, South Carolina has a lower rate than the U.S. for motor vehicle accidents. In the other causes of death in this age group South Carolina is very close to the national rates. (See Graph 3.1.2p)

Table 3.1.2c South Carolina Ten Leading Causes of Death in Children Ages 1-4 1997

1-4 Years	White	Black	Total	Rate
Accidents	25.0%	30.6%	28.4%	11.1
Motor Vehicle Crashes	3.1%	4.1%	3.7%	1.4
Other Accidents	21.9%	26.5%	24.7%	9.6
Infectious & Parasitic Diseases	15.6%	26.5%	22.2%	8.7
All other diseases	18.8%	16.3%	17.3%	6.7
Malignant Neoplasms	18.8%	4.1%	9.9%	3.9
Diseases of Heart	9.4%	8.2%	8.6%	3.4
Homicide	3.1%	12.2%	8.6%	3.4
Congenital Anomalies	6.3%	4.1%	4.9%	1.9
Ill-defined conditions	3.1%	6.1%	4.9%	1.9
Meningitis	0.0%	4.1%	2.5%	1.0
Pneum				1.0

onia 25.0 20.0 15.0



3.1% 2.0% 2.5% Total 100% 100% 100% In children ages 5-9 (Table 3.1.2d), cancer (malignant neoplasms) is the second most common cause of death. The remainder of the leading causes of death in this population are acute or chronic illnesses, including pulmonary diseases, health diseases, and infectious and parasitic diseases. Black and other children in this age group are almost twice as likely to die from a motor vehicle accident than white children. Black and other children are also more than four times as likely to die from infectious and parasitic diseases, diseases of the heart, or pneumonia than white children in this age group.

Table3.1.2d South Carolina Ten Leading Causes of Death in Children						
	Age 5-9 1997					
5-9 Years	White	Black	Total	Rate		
Accidents	66.7%	47.8%	56.3%	10.6		
Motor Vehicle Crashes	45.8%	26.1%	35.4%	6.7		
Other Accidents	20.8%	21.7%	20.8%	3.9		
Malignant Neoplasms	8.3%	8.7%	8.3%	1.6		

Malignant Neoplasms All other diseases 0.0% 17.4% 8.3% 1.6 8.3% 4.3% 6.3% 1.2 Congenital Anomalies Pulmonary Diseases 4.2% 4.3% 4.2% 0.8 *Ill-defined conditions* 4.2% 4.3% 4.2% 0.8 Infectious & Parasitic Diseases 0.0% 4.3% 2.1% 0.4 Diseases of Heart 4.3% 2.1% 0.4 0.0% Pneumonia 0.0%4.3% 2.1% 0.4 Other Respiratory 4.2% 0.0%2.1% 0.4 **Total** 100% 100% 100%

In children ages 5-14, motor vehicle crashes are the most common cause of death, and the rates for the past three years are higher than the U.S. rate. In other causes of death, South Carolina death rates are similar to the national rates (see figure 3.1.2q).

In children ages 10-14 (Table 3.1.2e), malignant neoplasms are the second, and other diseases the third most common causes of death behind accidents. Suicide and homicide are also among the ten leading causes of death in this group. Black and other children in this group are two and one-half times as likely to die from suicide or homicide than white children in this age group.

Fig. $3.1.2 \, q$ Mortality Rates for Children Ages 5-14

Table 3.1.2e Ten Leading Causes of Death in Children Age 10-14
1997

48.8%			
40.0%	47.1%	48.0%	14.2
29.3%	20.6%	25.3%	7.5
19.5%	26.5%	22.7%	6. 7
7.3%	14.7%	<i>10.7%</i>	3.2
7.3%	2.9%	5.3%	1.6
2.4%	8.8%	5.3%	1.6
7.3%	2.9%	5.3%	1.6
7.3%	2.9%	5.3%	1.6
7.3%	2.9%	5.3%	1.6
2.4%	5.9%	4.0%	1.2
2.4%	2.9%	2.7%	0.8
2.4%	2.9%	2.7%	0.8
100%	100%	100%	
	19.5% 7.3% 7.3% 2.4% 7.3% 7.3% 7.3% 2.4% 2.4% 2.4%	19.5% 26.5% 7.3% 14.7% 7.3% 2.9% 2.4% 8.8% 7.3% 2.9% 7.3% 2.9% 7.3% 2.9% 2.4% 5.9% 2.4% 2.9% 2.4% 2.9% 2.4% 2.9%	19.5% 26.5% 22.7% 7.3% 14.7% 10.7% 7.3% 2.9% 5.3% 2.4% 8.8% 5.3% 7.3% 2.9% 5.3% 7.3% 2.9% 5.3% 7.3% 2.9% 5.3% 2.4% 5.9% 4.0% 2.4% 2.9% 2.7% 2.4% 2.9% 2.7%

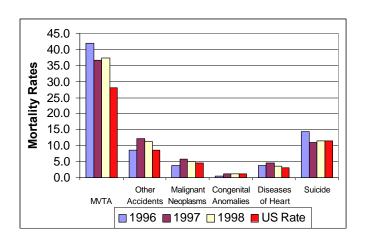
In adolescents age 15-19 (Table 3.1.2f), homicide is the second most common cause of death, and suicide is the fourth most common cause of death. White teens in this age group die from motor vehicle accidents twice as often as black teens. Malignant neoplasms are more than eight times more common in white teens than black teens.

Table 3.1.2f South Carolina Ten Leading Causes of Death in Children
Ages 15-19 1997

15-19 Years	White	Black	Total	Rate
All Causes				85.5
Accidents	63.6%	44.3%	55.0%	47.1
Motor Vehicle Crashes	53.8%	32.1%	44.1%	37.7
Other Accidents	9.8%	12.3%	10.9%	9.3
Homicide	28.8%	22.6%	13.4%	11.5
All other diseases	5.3%	10.4%	7.6%	6.5
Suicide	8.3%	6.6%	7.6%	6.5
Malignant Neoplasms	7.6%	0.9%	4.6%	4.0
Diseases of Heart	3.0%	6.6%	4.6%	4.0
Congenital Anomalies	0.8%	1.9%	1.3%	1.1
Infectious & Parasitic Diseases	0.8%	0.9%	0.8%	0.7
Diabetes	0.8%	0.9%	0.8%	0.7
Pneumonia	0.8%	0.9%	0.8%	0.7
Ill-defined conditions	0.0%	1.9%	0.8%	0.7
Other Respiratory	0.8%	0.0%	0.4%	0.4
Total	100%	100%	100%	

In the 15-24 age group, motor vehicle crashes were by far the most common cause of deaths, with suicides second. The death rates for motor vehicle and other accidents in South Carolina for the past three years has been higher than the

Fig. 3.1.2 r Mortality Rates for Children Ages 15-24



national rates. Death rates for suicide in this age group is close to the national rate (see figure 3.1.2r)

In young adults ages 20-24, homicide is the second most common cause of death, and suicide is the third most common cause of death. Homicide is more than five times more likely to occur in black young adults than white, but, suicide is almost four times more common in white young adults than black young adults. It is significant to note that by far the vast majority of deaths in these age groups are preventable.

Table 3.1.2g South Carolina Ten Leading Causes of Death
Ages 20-24 Years 1997

20-24 Years	White	Black	Total	Rate
Accidents	45.0%	37.4%	45.0%	47.5
Motor Vehicle Crashes	34.3%	28.2%	31.7%	33.4
Other Accidents	10.7%	9.2%	13.3%	14.1
Homicide	5.9%	28.2%	<i>15.7%</i>	16.5
Suicide	20.1%	5.3%	13.7%	14.4
Malignant Neoplasms	7.1%	6.1%	6.7%	7.0
All other diseases	6.5%	3.8%	5.3%	5.6
Diseases of Heart	3.6%	5.3%	4.3%	4.6
Infectious & Parasitic Diseases	1.2%	4.6%	2.7%	2.8
Cerebrovascular Disease	1.2%	1.5%	1.3%	1.4
Diabetes	0.6%	1.5%	1.0%	1.1
Other Circulatory	0.6%	0.8%	0.7%	0. 7
Pulmonary Diseases	0.6%	0.8%	0.7%	0. 7

Congenital Anomalies	0.0%	1.5%	0.7%	0.7
Other Respiratory	0.0%	0.8%	0.3%	0.4
Ill-defined conditions	0.0%	0.8%	0.3%	0.4
Total	100%	100%	100%	

Table 3.1.2h shows Mortality Rates for selected causes of death by age group. The mortality rate for motor vehicle accidents in the 0-14 age group is just over 6 deaths per 100,000. The mortality rate in the 15-24 age group is more than 5 times as high. One explanation of this is that most of this group is of legal driving age and may contain both inexperienced and irresponsible drivers. The mortality rate for suicide for the older teens (age 15-19) is 3.23/100,000. The rate in young adults (20-24) is triple that for the 15-19 age group.

Table 3.1.2h Mortality Rates for Selected Causes of Deaths by Age Group
1997

Cause of Death	Age Group Deaths		Population	Rate*	
Motor Vehicle Crashes	0-14	51	771,494	6.61	
	15-24	200	562,816	35.54	
Suicide	15-19	9	278,416	3.23	
	20-24	29	313,738	9.24	
Unintentional Injuries	0-14	34	771,494	4.41	

^{*}Deaths per 100,000 populations

Health Care

Currently, an estimated 20% of children less than 18 years of age are without health insurance coverage, and probably twice as many more with inadequate health insurance. Figure 3.1.2s shows the percent of health insurance coverage of children from the 1997 National Survey of America's Families. Black and other children of all ethnicities are much more likely to be publicly insured than white children. The proportion of children uninsured by ethnic group ranges from 16.4% for black children to 48% for Native American children. These groups should be considered high-risk, vulnerable populations and services need to be targeted to their specialized needs.

Vaccines

Table 3.1.2k shows the Vaccination Coverage in 2 year olds. Immunization compliance ranged from 89-97% in 1997 depending on type of vaccine and series. There was an improvement of 1-2 percentage points for most vaccines in 1998. The exception is Varicella, which is a relatively new vaccine, and only about 45% of 2-year olds received this vaccine. Our survey shows a great improvement in the number of 2-year olds who have finished the complete vaccination series (figure 3.1.2t). South Carolina has improved from just over 60% of 2-year-olds fully immunized in 1993 to approximately 97% in 1998.

Table 3.1.2k. South Carolina Immunization Coverage in 2-Year Olds

Single Vaccines	Dose	1997	1998	Combined Series	1997	1998
				Vaccines		
DTP/DT/	>3	98.7%	99.6%	4DTP/3Polio/1MMR	90.9%	91.9%
DtaP DTP/DT/	>4	91.9%	91.9%	3DTP/3Polio/1MMR/	95.1%	94.8%
DtaP Polio	>3	97.0%	98.7%	3Hib 4DTP/3Polio/1MMR/	90.7%	91.8%
Hib	>3	94.9%	94.8%	3Hib 3DTP/3Polio/1MMR/	89.2%	91.5%
MMR	1	96.4%	99.0%	3Hib/3HB 3DTP/3Polio/1MMR/		43.7%
				3Hib/3H		

B/1Var

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	PERCENT		
	Uninsured	Publicly Insured	Privately Insured
Black, Non-Hisp	16.4	53.0	30.7
White, Non-Hisp	18.5	30.3	51.2
Asian/Pacific Is	18.8	42.5	38.7
ALL RACES/ETH	21.0	39.3	39.6
Hisp, All Races	29.4	44.2	26.5
Native Amer/Esk	48.0	37.0	15.0

Fig. 3.1.2 s Health Insurance Coverage Of Low-Income Children

of America's Families.

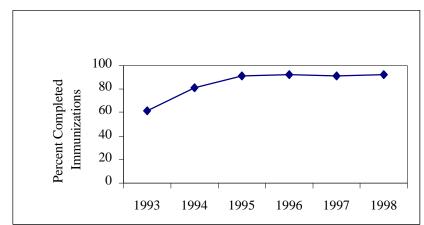
97.2%

99.0%

Varicella 1 44.9%

> 3

Figure 3.1.2t South Carolina Results of Immunization Survey of 2 Year Old Children



Unintentional Injuries

Unintentional injuries are a significant health problem with children and youth in

South Carolina. Table 3.1.2j shows the most common causes of injuries that do not result in fatalities for the State of South Carolina for children and teens. Falls are the most common cause of injuries in the 0-14 age group, with motor vehicle crashes second. Motor vehicle crashes are the most common cause of injuries in the 15-19 year age group. The rate of Hospital Discharges and ER visits for motor vehicle crashes in the 15-19 year age group is more than 5 times that of the 0-14 age group. The 15-19 year old group is a much higher-risk group as many of these crashes may have been caused by a teenage driver. Many children in this age group are old enough to drive legally in most states, and

young, inexperienced and/or irresponsible drivers tend to have more accidents than more mature and experienced adult drivers do.

Table 3.1.2j. Rates of Hospital Discharges and ER Visits for Most Common Unintentional Injuries for Children and Youth in South Carolina (per 10,000 children and youth)

Age				
Group	Injury Cause	Discharges	Injury Cause	ER Visits
0-14	Falls	55.2	Falls	228.0
	Motor Vehicle Crashes	30.2	Struck by/against	159.7
	Poisoning	19.8	Cut/Pierce	75.6
	Struck by/against	14.7	Motor Vehicle Crashes	63.0
	Pedal cycles	13.5	Natural/Environmental	52.4
15-19	Motor Vehicle Crashes	162.7	Motor Vehicle Crashes	311.4

Sexual Behavior

Sexual behavior is an area of very high risk for teenagers. Sexually active teens are vulnerable to many and potentially life-altering and sometimes life-threatening problems, including pregnancy, STD's, and HIV/AIDS. Any of these problems have serious health, social and economic consequences for today's teens. Data from the 1999-South Carolina Youth Risk Behavior Survey (YRBS) indicates that 43.8% of adolescents have engaged in sexual intercourse by age 15, and 65.0% have engaged in sexual intercourse by age 17. This constitutes a huge segment of the adolescent population who are engaging in very risky behaviors. Some teens report that they are being pressured or forced into having sex. The YRBS reports 8.9 percent of adolescents who have been forced to have sexual intercourse by age 15, and 12.4 percent of adolescents who have been forced to have sexual intercourse by age 17.

STD's are a serious problem with South Carolina's children and young adults. South Carolina had the third highest chlamydia rate in the nation in 1997. Almost one half (49%) of chlamydia cases reported in 1997 were in the 13-19 age group. About 30% of gonorrhea cases and 7% of syphilis cases were in the 13-19 age group.

Teen Pregnancy

Despite the high number of sexually active teens reported in this state, the rate of teen pregnancy is decreasing. Trends for the past 10 years show a 31% decrease in teen pregnancies, and a dramatic 60% decrease in abortions to teens. Live births to teen have shown a 10% decrease over the same time frame. (See Fig. 3.1.2f and 3.1.2g in Pregnant Women and Infants Section).

The pattern of decreases in pregnancies, live births and abortions has been somewhat different for the different racial groups. In the white population, dramatic decreases have been shown in pregnancy and abortion rates, but live births have remained stationary over the past 10 years. In the black and other population, the decreases in pregnancy and abortion rates have been less dramatic, but the live birth rate has shown a sharper decrease. This trend may indicate

decreasing sexual activity among adolescents in the state since utilization of health department family planning services has not changed much in the past 10 years.

In South Carolina, available programs exist along a continuum, which provides adolescents with access to programs that address their current and potential risk status. These programs range from abstinence-only until marriage, including programs for preteens and their parents, which stress chastity as well as abstinence, to medical services for adolescents who are actively engaged in the highest risk taking behaviors. Not all programs are statewide. Primary prevention programs, which are mostly educational and instructional interventions, frequently occur at school, in the home, or in faith settings. Teenage pregnancy prevention advocacy groups have been effective in establishing these programs at the community level throughout the state.

Substance Abuse

Table 3.1.2m shows results of the 1999 YRBS regarding substance abuse. The respondents to the survey were students in public high schools, so any teens not in high school are not represented by this survey. The questions were asked in the form of "Have you used (substance) in the past 30 days?", with the exception of heroin, where the question was "Have you used heroin ever in your life?"

Table 3.1.2m. South Carolina Substance Abuse among High School Students*

Grade						Metham-
Level	Alcohol	Smoking	Marijuan	Cocaine	Heroin	phetamines
			а			
9 th Grade	38.8%	33.1	21.7%	3.7%	3.6%	7.8%
10 th Grade	48.4%	37.5	26.5%	4.2%	4.4%	8.8%
11 th Grade	45.2%	36.9	25.9%	2.6%	1.8%	6.9%
12 th Grade	52.1%	37.6	24.8%	2.9%	3.0%	7.8%
Average	47%	36%	25%	4%	4%	8%

^{*}Percent of Respondents to the YRBS survey when asked had they used any of the above substances

The results showed that approximately 47% of high school students used alcohol, and 36% had smoked in the last month. Drug use ranged from 4% for cocaine to 25% for marijuana. These results indicate that substance abuse is a serious health problem with teenagers in South Carolina.

Nutrition/Physical Activity

South Carolina's children and young adults rank high relative to those in other states with respect to the problems of overweight, obesity, and poor nutrition. Data from the United States Department Agriculture (USDA) shows that significant proportions of young children nationwide have diets that are insufficient with respect to needed amounts of iron, calcium, fiber and total energy. Iron deficiency, in particular, is a significant problem in that it is associated with

fatigue, impairments in physical and intellectual development, and lowered resistance to infections. Shortages also exist for the recommended daily intake of calcium, fiber, and total calories.

Summary reports from South Carolina's First Steps Initiative, a statewide program designed to identify opportunities for improving the health and well being of South Carolina's youngest children and their families, show that many households in the State experience hunger or food insecurity. These reports cite studies from the USDA indicating that 9% of all households in the State were food insecure in 1995. Nearly 3% of households experience moderate to severe hunger. Recognition of the fact that the welfare-to-work initiative has decreased reliance on public assistance programs carries with it the knowledge of a need from private help from food banks, churches, and civic organizations. The very young, the very old, and the working poor are most at risk. Public Health should address this need by identifying food resources for the groups and by disseminating accurate nutrition information and assuring access to nutritious foods.

Children and adolescents in the state seem to have, in general, poor eating habits. However, information on nutritional status and level of physical activity of South Carolina's children is sparse. One of the very few sources available, the 1999 YRBS, states that although fruit, vegetables, and salad were eaten at least once a week by 79%, 82%, and 57%, respectively of respondents, only 18% ate the recommended 5 fruits and vegetables, and 12% reported drinking 3 glasses of milk per day.

Information on obesity in the children and youth of South Carolina is not readily available. However, weighted estimates from NHANES III would indicate almost 140,000 overweight children and almost 70,000 obese children ages 6-17 live in the state. Using these estimates, approximately 21% of South Carolina's school age children are overweight and 10.5% are obese. Nationally, about one in five children have been reported to be obese. Prevalence rates by race and gender for children in South Carolina are not readily available.

Obesity is a disease that is much more easily prevented than treated after its onset. Strategies for prevention in school age children may include reducing the fat and calorie content of School Lunch meals, limiting the availability of high-fat, high-calorie snacks in schools, teaching nutrition in the classrooms, and encouraging increased physical activity in both in and out of the school environment. This is an emerging health problem, and one that is getting increased emphasis with respect to program planning now and in the very near future.

Population Group 3: Children with Special Health Care Needs

South Carolina assessed the needs of Children with Special Health Care Needs (CSHCN) according to a protocol that focused on two major areas of interest. The first area related to the young adults who, by age 18 and according to state regulation, became age-ineligible for continued services from the State's Children's Rehabilitative Services (CRS) program. The interest was in determining the extent to which their needs for health care and related services during this transitional period to adulthood are being met. The second major area of interest was to follow-up on the survey results of the 1995 Comprehensive CRS Assessment and to implement an expanded "second wave" of the study to assess

current capacity of South Carolina's system of health, social, educational, and related services to meet the needs of CSHCN currently in the system. Cross-sectional survey methodologies were used for both component parts of the Year 2000 Assessment. The findings and conclusions from this assessment are summarized in the following by the two major focus areas. Full reports for both areas are located in the Appendix section of this document: Appendix E for the follow-up to the 1995 survey, and Appendix F for Young Adults in Transition.

CRS Survey on Transitional Needs for Young Adults with Special Health Care Needs

Method:

How survey participants were selected. A list of 1,033 names and addresses from the CRS client archive was obtained to conduct the survey. To verify addresses for mailing the questionnaire, a letter and a self addressed, stamped post card were mailed to all (1,033) potential families. This enabled us to gain current addresses and information about the families' arrangement. Around 200 cards were returned. This indicated a need for a small motivational reward for completing and returning the survey, (i.e. a \$5.00 gift certificate was promised and mailed after the completed questionnaire was received).

How the survey was developed. A team of experts established ten domains of transition, based on national research. Then, a set of questions was developed to measure each of the domains. The questionnaire was field tested to make sure each question measured the intended domain.

Number of surveys mailed. The survey packet was mailed, including a copy of questionnaire to the non-respondents on three occasions.

Number of responses received. Of those surveys that were delivered to the target population (760), a large number went unanswered 480 (63%), 10 (1.3%) refused, one was deceased and three were incomplete. Thirty -five percent (267) completed questionnaires were received.

General summary of results. The majority of the young adults responded indicated they had received some kind of transitional services from a public health setting. Only 34 (14%) of 246 respondents did not receive any transitional services. From the 246 who answered the transitional questions, they indicated their school provided mostly the transitional services securing employment, college and job training. South Carolina Vocational Rehabilitation assisted them with securing jobs and CRS in DHEC assisted them with their transition from pediatric care to adult care.

Problems Identified.

- There are disparities in services for CSHCN by geographic location (rural areas have less services), age and type of disability.
- Adult care providers are not adequately trained to meet the needs of young adults with special health care

needs.

- 41% (103) of the young adults surveyed declared their medical care needs as unmet. Most of these are younger black females who live with their family of 3 or more members.
- There are inadequate services for young adults dually diagnosed with mental health and medical needs.

Need for Direct Health Care Services

The survey documented a number of needs for direct health care services for young adults with special health care needs. Included among these are:

- A shortage of specialists, especially in rural areas.
- Adult care providers are not adequately trained to meet the needs of young adults with special health care
 needs. In a survey of young adults with special health care needs 37% of 175 stated that doctors were not
 familiar with their health condition.
- Inadequate dental care and funding for dental care services. In the CRS survey of young adults with special
 health care needs 69% of 263 expressed a need for dental care services. Also, out of 208 respondents, 69%
 expressed a need for assistance in paying for dental services.
- Inadequate services for children dually diagnosed with mental and medical health needs. Most young adults with special health care needs are under the care of more than one specialist, particularly if they have multiple disabilities. They need to have medical homes offering coordinated medical services. This is often not the case. Care is usually fragmented and inadequate.

Financial Barriers

- Need for increased funding for insurance coverage, especially for families affected by welfare reform and changes in SSI regulations.
- Need for improved coordination between service providers and sources of funding (agencies paying for different services).
- Need for adequate health care coverage for young adults with special health care needs. In the CRS survey
 of young adults with special health care needs, 34% of 265 had no health care coverage and 53% of 218
 indicated they were unable to pay their health care costs. Also, 75% of said they had no money, no Medicaid
 and no Insurance.
- Inadequate funding for medication. From the 267 young adults in the CRS survey, 64 (24%) needed medication but could not get it due to various reasons (no money, no medicaid, no insurance, unpaid bills).

Follow-Up Study of Needs for All CSHCN Children

As was true of the 1995 needs assessment for CSHCN, the ultimate purpose of this component of the present assessment was to gather information to improve policy decisions that foster service delivery systems for children with special health care needs that are coordinated, comprehensive, community-based, family-centered, and culturally competent.

To this end, a follow-up study to the 1995 Statewide Needs Assessment of Children with Special Health Care Needs gathered information to (1) determine needs following changes in services provided since 1994 (2) estimate the unmet needs for all services, (3) assess the content and timing of services, and (4) identify barriers to service delivery. The methodology developed to address these issues involved key informant interviews, focus groups, follow-up surveys and the appointment of an Advisory Committee.

The Advisory Committee consisted of a group of 16 individuals representing community-based parent organizations of children with special health care needs and staff from the DHEC and Maternal and Child Health Bureau. Their primary responsibility was to provide input into the overall design of the study, review the findings, and help frame final recommendations. The key informants were 15 individuals representing policy makers, agency administrators, health care providers, and advocates of children with special needs. Selection of the key informants was based on their familiarity with the health care system and their knowledge of children with special health care needs. Data were collected from eight focus groups drawn from caregivers who participated in the 1994 Needs Assessment and from those with similar characteristics who did not participate in the 1994 study. Two additional focus groups formed of young adults with disabilities and another consisting of the Title V Medical Advisory Group were also conducted. Forty-nine mail-out surveys to caregivers of children with complex medical needs that were under-represented in the state-wide focus groups constituted the final source of data gathering.

The needs identified were similar across geographic areas of the state and for both child and young adults with special health care needs. The needs documented for children with special health care needs included financial access to health care coverage, increased access to providers and linkages between health care and other components of the social system. In particular, the following services were seen as crucial in meeting the needs of these children:

- Increased insurance coverage across all age groups, especially those affected by welfare reform and changes in SSI regulations;
- Increased number of Specialty Care Providers to care for children with special health care needs;
- Equal coverage for mental health among the subset of children who require psychological services to facilitate adjustment to their disabilities;
- Increased availability to home health services was seen as crucial to meeting the needs of these children; and, finally,
- The expansion of eligibility requirements for children with complex medical needs.

Attainment of these goals requires increased coordination across agencies and providers to ensure continuity of care. This would entail coordinating "funding streams" among agencies to avoid duplication of services and to reduce "red tape" thereby facilitating a timely delivery of medical services. The need for greater coordination was particularly evident between school-based health services and health care providers. This linkage would enhance continuity of care and serve to maximize the child's potential for learning. An important barrier to improved care is the health services disparities in different geographic areas. The absence of specialty care clinics in rural areas requires excessive travel

by families and exacerbates the problem of adequate transportation of poor families. Although there were many similarities between children and young adults with special health care needs, the study identified several needs unique to the young adult population, particularly involving the transition from child to adult.

One such transition problem is the loss of Medicaid coverage after attaining the age of 19. This places young adults at risk for a break in continuity of the complex care that they have received throughout childhood. A closely related problem is the inadequate number of physicians trained to meet the special needs of young adults with disabilities and many providers of adult care have less experience in coordinating services with public agencies. The transition from school to the adult world may involve the necessity for further vocational training following high school and the fostering of independence requiring such services as training to self-administer medication, to avoid exploitation or assault, driver education or support for accessing some form of transportation and for those with more complex health care problems the possibility of respite care for families of young adults.

A summary of the priority recommendations for Children with Special Health Care Needs appears in Table 3.1.2l below.

Table 3.1.2l. Priority Recommendations for Children with Special Health Care Needs

- 1. Facilitate a multi-agency task force to address a coordinated system of care for CSHCN (to include, but not limited to, medical, psycho-social, education, and care giver supports) through a central point of entry and coordination of care.
- 2. Examine the system of respite care and develop recommendations to enhance the service.
- 3. Examine financial access for children with special health care needs, to include, but not limited to, provider reimbursement rates, insurance coverage, dental care, ancillary services [i.e. assistive therapies, personal care attendants, and durable medical equipment]; medications, waivered services (e.g., skilled nursing) mental health, long term care in compliance with federal mandates, respite care, and housing.
- 4. Formalize a plan to assure that all providers of services to children with special health care needs are appropriately trained to provide coordinated family centered, culturally competent, and community based care.
- 5. Facilitate the education and training of children with special health care needs and their families [to include, but not limited to, activities for daily living, post secondary education, vocational rehabilitation, self-advocacy, and independence and self-management].
- 6. Develop a transitional services system of care (to include, but not limited to, medical, psycho-social, and education).
- 7. Evaluate the existing transportation systems for children with special health care needs and their families and develop recommendations to improve access to transportational services.

3.1.2.2 Direct Health Care Services (with Enabling)

In South Carolina, expansions over the past 5 years in Medicaid eligibility and the incorporation of the CHIP Program in 1998 have substantially reduced financial barriers to health care (See Table 3.1.22a). Children ages 1 - 18 with family incomes up to 150% of the federal poverty level (FPL) are now covered, and the State legislature has

agreed to extend income eligibility to 165% of FPL for this group. Funding is not assured but anticipated. For children with special health care needs, expansions in the State Children's Rehabilitative Services program have been successful in extending service to the working poor. These expansions have allowed the State health department to begin to redirect its services to the core public health functions of assessment, assurance, and policy development. Public health staff are able to turn their attention to evaluating the efficiency and efficacy of State-funded health promotion and preventive health initiatives. Preliminary analysis of this new focus suggests that it has proved to be very beneficial in transitioning direct care services to mothers and children to private sector providers. Concerted efforts between primary care physicians in the private sector and DHEC family support services staff have forged strong public-private alliances has produced exemplary results in assuring that mothers and their families receive medical (direct) as well as enabling and supportive care.

Even with these signs of progress, many private care providers are still unable or unwilling to care for Medicaid enrollees, and children with no insurance at all are very much in need of assistance in obtaining needed services. Many children, including those with special health care needs, are unable to obtain routine medications for preventive as well as therapeutic care. Significant financial barriers related to inadequate health care coverage such as unemployment, insufficient funds to pay for insurance, no access to employer paid insurance still exist and must be addressed. There is a need for improved coordination between providers of care and agencies that pay for various health services.

Shortages exist in care providers of all types in rural areas. In all areas of the state, shortages exist in registered dieticians, nutritionists, mental health specialists, dentists, audiologists, and providers of adult specialty and sub-specialty care for young adults with special health care needs who are no longer eligible for services from the State CRS program. Shortages also exist for children with dual diagnoses of both medical and mental health problems. This is particularly true of children and young adults with special health care needs. Many in this population are under the care of more than one specialist, particularly if they have multiple disabilities. Low Medicaid reimbursement rates for specialists and sub-specialists (such as endocrinologists) have contributed to these shortages. Cross-sectional surveys of families of children with special health care needs identified needs for (1) home health services including skilled nursing and respite care; (2) training of Medicaid providers in assistive technology; (3) school-based health care services that include occupational, physical, applied behavioral, and speech therapists; and (4) driver's education classes. A clear need exists to remove the problems of fragmented care by ensuring that they have medical homes offering coordinated medical and other health related services.

Results of surveys combined with reports to public health program staff suggest that substantial numbers of pregnant women perceive social and cultural barriers that make them disinclined to seek prenatal, postnatal, and child health care services. The disadvantages of poverty, low social status, and the need for public assistance are reported to be experienced in terms of delays in getting appointments for health care, in obtaining the full range of

health care services, and in maintaining self-esteem as recipients of "charity" services. South Carolina's growing immigrant population is largely represented by migrant workers who have concerns that requesting health care and other publicly funded services will jeopardize their ability to continue to live in the state.

South Carolina is experiencing an increase in its Hispanic population. For example, births to Hispanic women increased by 19.4 percent in the past year, from 1,121 to 1,338 births. This illustrates the growing presence of Hispanics in the state. Need for direct and in particular enabling health care services among Hispanics is great. This population poses particular challenges due to language and cultural barriers found in the present day health care system. The health care system is just now beginning to identify these barriers and to implement initial enabling service responses. Attempts to begin to resolve some of these issues have begun particularly at the local level. Several areas have hired bilingual staff, and outreach to Hispanics is taking on greater importance.

Penetration of managed care health insurance systems has been low in South Carolina relative to other states. Currently, only a small percentage (about 10,000) resident children are covered by a partially capitated plan, so the impact of managed care has been minimal. However, observations of the restrictions that these children have in obtaining the scope of needed health services suggests that an increase in the proportion of children receiving services under managed care would be detrimental.

Welfare Reform

Through its close affiliation with its sister agency, the South Carolina Department of Social Services (DSS), DHEC is able to monitor the impact of the passage of welfare reform on the health status of mothers and children. DSS tracks former welfare receipts in their transition from welfare to work. To monitor this transition and to ensure that the social safety nets provided by the Family Independence Act, (FIA-- Temporary Assistance to Needy Families (TANF)) program are implemented, DDS conducts quarterly surveys of this population. The surveys compare former clients who are now employed with welfare receipts no longer employed or never employed. To date six independent surveys have been conducted by DDS and four of the six have been analyzed and reported. These four began in October, 1996 and ended in September, 1997. A major aim of these surveys is to evaluate the general well being of former welfare clients and their dependents.

Impediments in effecting a change from welfare to work consists in (1) being ill or injured or have family members with health problems, (2) the absence of transportation, (3) the lack of child care, or (4) inadequate job opportunities or job skills. Although only a partial remedy for family illness, 91 percent of former clients and 86 percent of current TANF recipients have some form of health insurance for at least one or more members of the household and for approximately the same percentages (86 and 85 percent, respectively), this insurance is Medicaid. The percentage of children (ages under 19) covered by Medicaid and private insurers varied from 82 and 16 percent, respectively, for former working clients to 79 and 5 percent, respectively for non-working receipts. There has been increasing Medicaid coverage for both groups from the first to the fourth survey.

Many households continue to receive other forms of assistance after welfare payments stop. Approximately the same proportion of working and non-working clients receive Medicaid and participate in the WIC, school lunch, summer feeding, and rent subsidies programs. As expected, a higher proportion of non-working clients receive food stamps than those working (67% vs. 55%, respectively) and SSI benefits (19% vs. 9%, respectively). In contrast but again as might be expected, a higher percentage of working clients receive child care subsidies (24% to 7%).

The lack of transportation remains an important hindrance to securing or maintaining employment, with only 51% of former clients and 31% of non-working clients having access to a vehicle. DDS provides supportive services to clients based on need in the form of purchased transportation, bus services, paid mileage, or one-time minor auto repairs. Efforts are made to inform former clients of these services even if they have left welfare for an extended time.

The welfare to work transition has created an increasing demand for child care services that is still not well met and continues, we believe, to represent a significant barrier to ensuring the health and well-being of children. Although the percentage of working clients receiving child care services and child care subsidies has increased over the course of the surveys (87% receiving child care services and 39% child care subsidies in the last survey) so that problems in getting or paying for child care have lessened, child care problems continue to affect a significant portion of former clients' ability to get or retain employment. For example, 16% of working clients report instances where child care was either unavailable or that they were unable to pay for it.

Discussions with Needs Assessment committee members, coworkers in the Health Districts, and with staff members in other State agencies have identified essentially three areas of concern regarding access to health care and health-related services from the perspective of financial access, cultural acceptability, availability of prevention and primary care services, and availability of specialty care services. These are (1) concentration of health-care and health related services in urban areas; (2) changes in the demographic profile of women, infants, and children resulting from immigration, primarily of Hispanic populations, into the state; and (3) challenges in the State's capacity to monitor and assure quality of care as the role of DHEC diminishes over time in the provision of direct health care service. DHEC and its partner agencies and providers are strongly invested in developing methods to identify those in need of direct health care services, and to secure for each of them a "medical home," where direct-and health-enabling care is accessible, family centered, continuous, comprehensive, coordinated, compassionate, and culturally competent.

The Health Department continues to be a point of access to health care. In very rural areas, the Health Department is often easier for the client to access than a primary care practice (PCP) group. The Health Department serves as a referral source to other providers, but also is continuing to provide some direct services, such as associated with the Family Planning waiver. We have been able to put our staff into the community, physician's offices, schools and hospitals in order to meet the needs of our community. Due to these collaborative efforts, the number of children

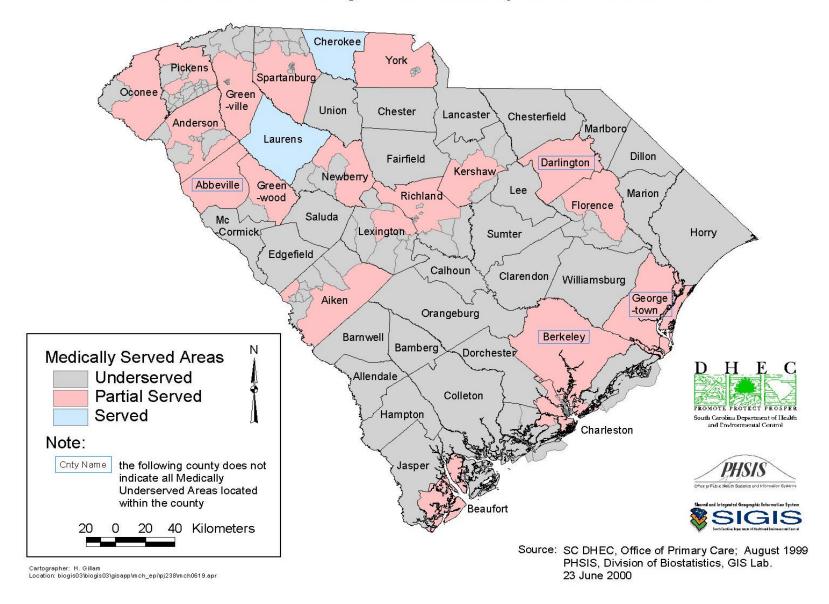
who have medical homes continues to increase. Family Support Services (FSS) are being marketed to the Private Providers, hospitals, as well as utilizing existing community channels, such as our DHEC-employed school health nurses. This has the potential of greatly expanding FSS. The early initiation of newborn home visits yield timely identification of health risks, educational needs and serves as a key to linkage to systems of service. Health Promotion efforts in the community impact the community's level of awareness and importance of preventive health.

Linkages

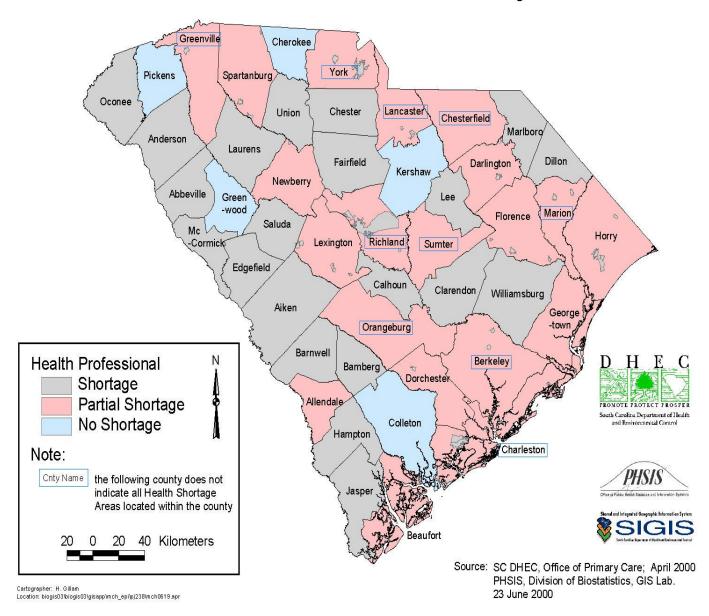
South Carolina-DHEC's 13 Public Health Districts in combination with its array of professional, financial, and multi-disciplinary family and community-based advisory committees represent the linkages that exist to promote provision of services and referrals between primary level care, specialized secondary level care, and highly specialized tertiary care. A complete listing of DHEC's advisory committees is contained in Appendix A.

Areas identified in need of improvement are primarily centered around the coordination of care. In particular, providers of services to young adults with special health care needs are often not sure of the availability of referral resources or of the protocols to follow to accomplish referrals. For the MCH populations in general, there is a perceived lack of coordination between providers and funding sources, and the mention of "red tape" due to turf protection across funding agencies. Improved coordination of care across providers in the private and public sectors is needed in order to minimize costly duplication of data collection, screening, assessment, and services.

South Carolina Designated Medically Underserved Areas



South Carolina Health Professional Shortage Areas



3.1.2.3 Enabling Services

See above.

3.1.2.4 Population-Based Services

Population-based services, as the name implies, are public health services that are available to the population at large. The population-based services in the state of South Carolina fall, in general, into one of two categories, preventive health care programs, or educational efforts. Preventive health care programs are focused on preventing and/or reducing health problems and tend to include programs such as immunizations, newborn home visits, newborn screenings for inborn errors of metabolism and hearing, lead screening, and school health programs. Educational programs are generally aimed at improving and promoting health and wellness and may include education on parenting skills, nutrition, safety, domestic violence, and substance abuse.

Preventive Health Care Programs

Preventive health care programs include immunizations, newborn home visits, newborn screenings for inborn errors of metabolism and hearing, lead screening, and school health programs. These programs are available to the general population who has a need for them and are available in all areas of the state.

Immunizations

Immunization services for infants, children, adolescents, and adults are made available through the South Carolina Vaccine Assurance For All Children (VAFAC) Immunization Partnership. This public-private partnership continues to grow and includes all local county health departments, 99.9% of the private pediatricians' practices in the state, a large proportion of family practices, all colleges and universities, all rural health clinics and community health centers. Current non-DHEC enrollment in VAFAC is 492 immunization practices. This partnership continues to garner support from the medical community where it has emphasized the importance of a single medical home from its inception. Most providers say that immunization is the carrot that gets the child in to see the doctor.

Both national and state data demonstrate successful childhood and adult immunization programs in South Carolina. The agency's adolescent immunization initiative, which was begun in 1996, will result in school grades K-12 second dose measles protection in the school year 2000-2001, and the same level of protection against hepatitis B virus infections by school year 2003-2004.

The main focus of immunization programs is to prevent disease through vaccination. Two thirds of the immunization activities in the state are targeted toward infants and preschool-aged children to prevent diseases for which vaccines

have been made available. The remainder of immunization activities in the agency are divided among adolescent, adult, employee, rabies, disease control, and international travel immunization programs.

Nutrition

Nutritionists are available in South Carolina's 13 public health districts as well as the Central Office. A wide variety of programs utilize the services of nutritionists, as nutritional status is a critical component of overall health. Some of the functions that nutritionists have at the local level include WIC Program certification and counseling, medical nutrition therapy, nutrition assessment, work with the community on wellness, providing nutrition education by individual counseling sessions, group classes, and community outreach. Nutrition professionals at the state level function to provide consultation and support to local nutritionists and other state and local program staff, provide input for policy and standards of care, conduct nutrition-related research, and prepare and disseminate appropriate nutrition education materials.

The need for nutrition services is ever-expanding. A chronic shortage of qualified nutrition staff exists state-wide, but is particularly critical in rural areas.

Newborn home visits

Newborn home visits are done for all infants that are Medicaid-eligible and may be offered to others as well, within 2 weeks of hospital discharge. The primary purpose of these visits is to link the newborn into a medical home. Another purpose of these visits is to assess the infant for potential health problems, assess the home environment for any potential problems and safety concerns, and offer education and support for the parents on issues such as feeding, bathing, and other needs or questions the parents may have. This visit also serves as a "gateway" for Family Support Services when needs are identified.

Newborn Screening

One important service that DHEC sponsors is screening initiatives for newborns, including screening for both metabolic abnormalities and potential hearing problems. These are critical for the health of children to diagnose these conditions as early as possible to initiate treatment that will maintain the health of these children. All infants born in South Carolina are required by law to be screened for metabolic disorders and hemoglobinopathies. At present infants are tested for phenylketonuria (PKU), congenital hypothyroidism (CH), galactosemia (GAL), congenital adrenal hyperplasia (CAH), and hemoglobinopathies. Screening for medium chain acyl co-A dehydrogenase is also being done. See Form 8, Section 5.8.

The greatest need for these programs involves needs for equipment, follow-up, tracking, and treatment of newborns with positive screens.

Lead screening

DHEC expanded its blood lead screening efforts in April, 1999 to include all one and two year old children statewide

who access the health department for WIC services. This group of children was targeted because CDC research indicates that low income one and two year old children are most at risk for lead poisoning. Participation in the WIC program can be an indicator for low income status. Other children are screened based upon individual risk factors. At this time, around 3,500 children across SC are being tested for lead each month. Data from this expanded screening will be used to set childhood lead poisoning prevalence rates for SC communities. This data will allow DHEC to issue screening guidelines that will be specific to the risks in each community.

School health

Partnerships between DHEC and schools exist statewide. The exact nature of these partnerships vary from county to county. In some areas the school nurses are DHEC employees who have been placed in the schools. In others, the nurses are employees of the school system who work very closely with DHEC in a variety of areas. Some of these areas may include child health and EPSDT exams, immunizations, education on a number of issues, and working with the DHEC Family Support Services staff on social and domestic issues involving school-age children.

The greatest need in this program, as in many others, is a shortage of qualified staff. Many districts report a very high student-to-nurse ratio, especially in rural areas.

Care Line

Care Line is a statewide, toll-free hotline, which provides information, referrals, assistance and support to women for their children and families. The goal of the Care Line is to improve access, and utilization of, health care and health-related services by identifying and addressing problems callers are experiencing. The Care Line Access Information System maintains data about the problems reported by clients and services provided by the Care Line staff. Calls are reported by county and by program area. For the period January 1999 to December 1999, there were 10,803 calls. The Care Line documents calls in the following four program areas administered within Community Health at DHEC: Prenatal/Postpartum, Family Planning, Infant/Child Health, Children's Rehabilitative Services (See Form 9, Section 5.8).

Educational Efforts

The second area in which DHEC provides population-based services is in educating the public on a variety of issues. DHEC employs a wide variety of methods used in getting its messages out to the general public. These include public awareness campaigns, classes offered on a variety of subjects, individual counseling sessions, and educational literature published by DHEC. Public awareness campaigns may include television and radio spots, billboards, internet web sites, posters, and other types of literature.

The issues that DHEC provides education to the MCH population on are many and varied, most having to do with health promotion and prevention of injury and diseases. These include the importance of prenatal, pre-interconceptional care, nutrition, teen pregnancy prevention, STD's, particularly HIV transmission, and parenting

skills. Other issues having to do with safety and healthy lifestyles include education on injury prevention, domestic violence, wellness promotion, health and fitness, substance abuse, and other health concerns. Some specific examples of educational programs include the "Back to Sleep" campaign, co-sponsored by the March of Dimes, the Folic Acid Campaign, and the car seat promotion program.

In summary, the population-based programs serve as primary prevention strategies by education on a variety of health issues, and screening for a variety of health problems.

3.1.2.5 Infrastructure Building Services

Infrastructure building involves activities such as needs assessment, evaluation, planning, policy and standards development, coordination of services, quality assurance, monitoring training, applied research, systems of care and information systems.

Activities at the Local Level

Information related to infrastructure development at the District, County, and Community levels is discussed here, and this information is grouped into five major categories: (1) Needs Assessment, Evaluation, and Health Planning, (2) Policy Development and Implementation of Standards of Care, (3) Coordination of Systems of Health Care, (4) Quality Assurance, Monitoring of Program Effectiveness, Applied Research, and Information Systems, and (5) Training.

Needs Assessment, Evaluation, and Health Planning

DHEC is involved in a number of efforts toward Needs Assessment, Evaluation, and Planning at the local level. Representative examples of these efforts illustrate this involvement.

- Partners for a Healthy Community is an organization consisting of public and private sector
 representatives whose primary goal is to form effective, community-based partnerships for health. Its
 primary activities involve conducting formal assessments of health needs and promoting public awareness
 of programs, services, and activities concerning healthy lifestyles that seek to improve the overall health
 status of the community.
- Healthy Ventures is another partnership organization that includes representatives of DHEC staff, the Oconee Memorial Hospital, and other community interest groups. Healthy Ventures seeks to create a shared vision of health within the community; continuously assess the health needs of the community in light of this vision; identify partnership opportunities; provide health resource information to the community; employ a youth assets model to provide incentives designed to promote healthy lifestyles; implement asset-mapping throughout the community; and improve access to primary care in the County.

The major needs in this area are:

- Strategies for involving the recipients of Maternal and Child Health related services in health planning, health promotion, program development, and self-advocacy.
- Access to local community and county-specific data in a timely manner and an easily understandable format.

Policy Development and Implementation of Standards of Care

Partners for a Healthy Community, Healthy Ventures, and other similar initiatives are also involved in policy and standards development. Some of the ongoing goals are to develop integrated health policies which effectively link the health effects of all major areas of public policy (housing, education, transportation, employment, welfare, and health care), and serve as advocates for achieving adequate financing for health promotion and disease prevention. The needs in this area are:

- To develop and implement policies to broaden the baseline scope of services for women of reproductive ages, and for women with chronic illnesses.
- To educate public, private, and third party sectors about the incidence, prevalence, and public health consequences of STD's and other communicable diseases.
- To develop and implement policies to broaden the scope of screening to include all women at risk.
- To assist public, private, community and political leaders in developing and maintaining an attitude that unintended pregnancy is a health care issue as opposed to one of sexuality and morality.
- Conduct efforts aimed at increasing awareness of the adverse health consequences associated with use of tobacco, illegal drugs, and alcohol.
- Develop and implement policies aimed at assuring that all women of reproductive age receive an annual exam to include pre-conceptional counseling.
- Develop and implement programs that assure all pregnant women will receive appropriate prenatal care.
- Assure all women of reproductive age access to adequate nutritional resources and services.
- To ensure the enrollment of uninsured children into the State's Child Health Insurance Program, Partners
 for Healthy Children, and promote expansion of the program to children in all low income families.

Coordination of Systems of Health Care

DHEC has traditionally been the hub in the wheel of health care for many communities, interacting regularly or on an as-needed basis with a wide array of providers. These providers have had long-standing relationships with local hospitals, community health centers, and physicians' practices. In addition, the Health Department works closely with other agencies in the state from the public as well as the private sector. Included among these are the Department of Health and Human Services, the Department of Education, the Department of Social Services, the Department of Drugs, Alcohol, and Other Drug Abuse Substances, the South Carolina Medical Association, the Chapter of the American Academy of Pediatrics, the OB/GYN Society, the South Carolina Pediatric Association,

and many other private, public, professional, and community groups

The development and expansion of partnerships with private providers and agencies in the community is a major initiative that enables physicians to offer comprehensive health care services in their practice settings.

The development and expansion of partnerships with private providers and agencies in the community is a major initiative that enables physicians to offer comprehensive health care services in their practice settings. Partnerships may be formalized with contracts or may be informal collaborations between DHEC and private provider staff. These partnerships may involve placement of DHEC staff in private physician's offices or hospitals to provide referrals and follow-up for EPSDT and prenatal care, or to provide nutritional therapy or social work consultation, or they may be limited to referral networks supported principally by DHEC's Family Support Services. Preliminary analyses of the impact of this partnership initiative indicate that it has demonstrated clear evidence of meeting its intended goal, which is strengthen the client's perception of the medical home as the location for all of his or her health care needs.

Many communities have developed health-promotion initiatives over the last five to six years and have involved DHEC in the development of community improvement plans. These groups have felt that it was important to establish a strong infrastructure of leadership that was diverse, comprehensive, and action oriented. Board members representing these groups tend to be informal community leaders who are residents of the communities and who are committed to improving the health and well-being of their fellow residents. DHEC plays a major role in these organizations as members of boards, advising on community development and collaboration, being a catalyst for change, policy development, and quality assurance.

Agency staff provide input through a variety of community task forces, coalitions and boards such as the council for the Prevention of Teen Pregnancy, Vital Links, Success by Six, First Steps, Safe Kids Coalition, Perinatal Board, FIMR, NICU Discharge Planning committees, and Healthy Families S.C. Agency input has a strong influence on the inter-relationships of systems impacting the MCH population.

These systems are continually being refined and strengthened as the agency expands its role in coordination of community based care. Also the agency's roles continue to evolve in the face of health care reform, particularly in the areas of service coordination and systems development.

Systems of care are similar for Medicaid and for indigent patients. Since 1990, as a result of DHEC's Provider Partnership initiative, there has been an increase in the number of private physician practices willing to accept Medicaid payments, and a consequent increase in the number of Medicaid children that are receiving care from the private sector as the Health Department transitions out of this role. This has come about as a result of the increase in the Medicaid reimbursement rate, the support from Family Support Services, and an increase in the number of

children eligible through Partners for Healthy Children.

Infrastructure building efforts are ongoing to ensure a less fragmented, more effective system of care. The MCH populations need support to access these health care options. The role of DHEC continues to evolve as the environment changes. District staff are solidly in the community, initiating and participating in new partnerships to improve outcomes for the MCH population. First Steps, Success By Six, Born to Read, Back to Sleep, and Breast feeding Initiatives, among others are visible and well received in the communities. Community leaders are beginning to recognize the value of health in the overall lifestyle of the population.

Recognition of the strong history of DHEC's role in the community facilitates increased opportunities for collaboration and partnerships. The medical community throughout the state respects and supports knowledgeable nursing and other professional staff. Partnerships continue in most counties with pediatric and family practice physicians, who are actively committed to seeing that infants and children are linked into a system of medical care.

A large proportion of the strategic planning activities in the State's health districts are designed to ensure continued linkages between the Health Department and private sector providers. The following are examples of local infrastructure efforts taken from the SFY 2001 district MCH plans:

- In one district, Public Health Nurses visit each hospital daily to identify Medicaid or uninsured infants. At this hospital visit, a primary care physician is identified, WIC services are initiated, and Family Support Services are offered. A plan is developed for the nurse to visit the infant and the mom in the home within 48-72 hours after discharge from the hospital to complete all components of the maternal infant assessment. Family Support Services are provided to the mother, infant, and family as risks are identified. Prevention, anticipatory guidance are the focus of staff efforts. Partnerships continue with physician groups to assure infants have a medical home, keep their well baby appointments, and are up to date with their immunizations. An interdisciplinary approach is used to promote access and identify resources throughout the district.
- A collaborative partnership with DHEC exists in the health component at Headstart and Early Headstart programs in some counties. Health screenings are performed on the identified Headstart children to identify health or developmental risks. Assessments are performed, linkages to physicians, dentists, and health department services are provided, based on identified need. The health department staff are a resource to each Headstart Center and are actively involved on the Policy Council and on the Health Advisory Committee.
- The Health Department in one area has a MCH Discharge Coordinator located on-site at the hospital who
 serves as a liaison with private physicians to identify infants early in order to link back into the system of care.
 Referrals are made to Healthy Start for appropriate Family Support Services and tracking, with the goal being
 to decrease infant mortality.
- School Health Services are continuing to expand in some areas through a partnership with the school districts.
 A positive outcome of this initiative is measured in the increased number of children being enrolled in

Medicaid, an increase in children who have medical homes and a decrease in the absentee rate. In order to promote communication and networking among the schools, a school coordinator is on staff and routine meetings with the School Health Partners occurs throughout the year. EPSDT, vision and hearing screenings are also supported by the Health Department in some schools which do not have a DHEC school nurse on-site. Immunization efforts are on-going in all schools as the guidelines continue to change. Hep B for 6th graders is administered as well as offering immunizations to 12th graders preparing to go to college.

- In one district a Metabolic Coordinator works directly with private providers and Family Health Centers regarding utilization of support systems and linkage with the State Office of reportable cases. Successful collaboration with local hospitals, school districts and the community has impacted health services offered throughout the community. DHEC is represented on many county and district-wide task forces, boards and committees including, Covering Kids State Coalition, Sickle Cell Foundations, Health Ministries Alliance, and School Districts' Transition Collaborative which focuses on the special needs children transitioning from the school-age to adult population.
- A unique collaboration is occurring in Bamberg County among health-related state agencies. The development
 and implementation of the BCCSN (Bamberg County Community Services Network) has created a coordinated
 referral system which has also enhanced communication among these agencies. This system allows electronic
 referrals among the participating agencies/organizations and in Phase 1 of BCCSN, improved access to
 transportation for clients is the targeted goal.
- The Sickle Cell Transition Program in Palmetto Health District will be a joint effort of CRS, the James R. Clark Sickle Cell Foundation, SC Vocational Rehabilitation, Family Connections and Palmetto Richland Memorial Hospital Department of Hematology. This program will design and provide multi-disciplinary services to children with sickle cell disease to maximize health outcomes, improve school attendance and performance, enhance social skills, provide guidance for employment and/or higher education, and assist with transition to an adult system of care.
- CRS will provide a registered nurse for a pilot program for children with moderate-to-severe asthma in Richland county. This program will be a partnership between CRS, Pediatric Pulmonary Associates, and Palmetto Richland Memorial Hospital. The nurse will provide education and coordination of services in the physician's office, school and home. The goal of the pilot program is to improve health outcomes, improve school attendance, and reduce hospitalization, emergency room use, and polypharmacy.
- Several agencies in one area are working on a collaborative initiative, CAP (Community Access Program), to assist communities and consortia of health care providers to develop the infrastructure necessary for integrated health systems that coordinate health services for the uninsured and underinsured. Expected results include a system of care that provides coordinated coverage, increase access to primary care, elimination of unnecessary, duplicate functions in service delivery, and increase numbers of low-income uninsured people with access to a full range of health services.
- The Charleston County Infant Mortality Council meets quarterly to address issues related to pregnant women.

 This group has been instrumental in developing brochures, refrigerator magnets and a film on fetal

movements. They continue to work toward implementation of Babies and You, a national March of Dimes Project which provides prenatal education in the work place. They have also been working with the Zeta Sorority to develop a Storks Nest which would provide women with necessary items both during the prenatal period and after delivery.

A dental program has been initiated in partnership with MUSC School of Dentistry to provide dental sealants
to children in elementary schools. The Health Educator in this program is also working with local dentists
to enroll them as Medicaid providers.

While much progress has been made in care coordination at the local level, much is yet to be done. The following are still needed to strengthen our efforts:

- A multi-agency task force to address a coordinated system of care for CSHCN (to include, but not be limited to, medical, psychosocial, education, and care-giver supports) through a central point of entry and coordination of care.
- A transitional services system of care to include, but not be limited to medical, psychosocial, and educational services.
- Partnerships between providers of care should exist in every county to assure medical homes and the coordination of services. The Public Health partner will promote adherence to established standards of care.
- Partnerships between schools in every county to promote integrated school health programs.
- Services for children with chronic illness.
- Improved access to risk-appropriate care for pregnant women with special needs.
- Programs that assure all women of reproductive age have access to primary health care services.
- Increased partnerships with private, public, and community organizations to educate pre-teens on issues of reproductive health and sexuality.
- Enhanced use of indigenous/lay community workers to convey messages to clients.
- Tracking systems of private providers.
- Blending of public and private providers.
- Access to healthcare for undocumented women, mainly Hispanic, who are not eligible for Medicaid.
 These women present many challenges including inability to speak the language, lack of understanding of the system, lack of transportation, etc.

Quality Assurance, Monitoring of Program Effectiveness, Applied Research, and Information Systems

Some counties have been very successful in developing Community Child Health and Safety Councils. Others are in the early planning stages. Discussions with community partners has led to increased awareness and focus on preventable deaths in children. Plans are to include FIMR activities in this partnership. This effort is slowly expanding across the state.

Quarterly program reviews are held in some districts to evaluate the impact and outcome of DHEC programs. This data is used for future plans. Some of the methods in use are record reviews, client surveys and focus groups, use of vital record and other outcome data, and use of program participation data. Needs in this area are:

- Development of partnerships with universities, pharmaceutical, and private entities to increase research efforts to address and prevent chronic illness and to provide evidence based recommendations to third party providers.
- Evaluate staff's ability and willingness to provide services in a non-judgmental way.
- Development of a comprehensive, consistent, and high quality data collection system that allows analysis and monitoring of current as well as evolving systems of health care.
- DHEC should assure that data are collected, analyzed, and disseminated in a timely way and in a format that supports health planning and stimulates thought about health policy.

Training

Training efforts are on-going. Current training efforts at the local level are focused on transitioning staff members from roles as direct service providers to that of providing enabling services such as referral, follow-up, and support. The current needs in this area are:

- More cultural diversity among public health (health service) providers.
- A "Next Step" to follow the extensive staff training on issues around customer service and cultural competency, to integrate and apply areas of training, and to hold staff accountable for the quality of care and services that they provide.
- Improved skills of staff in taking a good health history. Steps include: evaluating current knowledge, skills, and abilities of staff; developing individualized plans to address staff deficiencies; holding staff professionally accountable for performance, a plan to assure that all providers of services to CSHCN are appropriately trained to provide coordinated, family-centered, culturally competent, and community-based care.
- Staff with collaborative skills and partnership promotion strategies to elicit the formation of groups seeking
 to provide options of health care for people with no payor source or inadequate coverage.

Activities at the State Level

In order to promote an infrastructure that supports a comprehensive and seamless system of care for the MCH population, DHEC works with the state Medicaid agency and with all major provider groups to promote coordination.

Needs assessment at the state level include an ongoing effort to monitor health status indicators, performance measures, and evaluation of the gaps and barriers to health care for the MCH population.

One of the most exciting new initiatives occurring in infrastructure-building at the State level is the new State Systems Development Initiative (SSDI). This project involves a collaborative effort between the Bureau of Epidemiology, the Division of Biostatistics and the Office of Research Statistics at the Budget and Control Board to create a central

location for data storage and utilization. One of the functions of this project will be assistance in linking of all data sets containing data on the same population, such as vital records, WIC data, Medicaid claims, hospital discharge data, and any other available data sets. This would enable the tracking of cohorts of subjects over time, and yield information on the long-term effects of early health risks, such as low birth weight.

Coordination of Services

To address the coordination of services for women, we have four Regional Perinatal Boards. We also have representation on the Governor's Maternal, Infant and Child Council (the DHEC Commissioner chairs the Service Plan sub-committee) and the Maternal, Infant and Child council of the SC Medical Association. The DHEC Commissioner chairs an OB Task Force and local health departments are actively involved in teen pregnancy prevention councils and efforts promoted by the March of Dimes.

To address coordination of services for children (and in addition to above), we have the Commissioner's Pediatric Advisory Committee, the Family Medicine Advisory Committee, and the Medical Advisory for Children with Special Health Care Needs. To promote coordination of care for the Medicaid population, we have a contract with the state Medicaid agency to promote medical homes for children. We meet with that agency and all of our the local public health districts at least twice a month to monitor local partnerships. To promote safety for children, we are represented locally and at the state level on Child Health Safety Councils. There is also a Pediatric HIV/AIDS Advisory group to which we have MCH representation in concert with the STD/HIV Division.

Federal Ryan White CARE Act Title II funding for children who are HIV positive provides medical support services: medical care, medications, case management, and supportive services such as transportation, counseling, home health, and nutritional support to eligible persons with HIV disease and their family members. Across the state, eleven local HIV care consortia comprised of community agencies and clinics have coordinated and developed medical care and support services based on identified gaps in service delivery in their communities. A statewide drug assistance program (ADAP) provides FDA-approved medications to qualifying persons with HIV disease.

The CRS program in South Carolina collaborates with many other State Agencies as well as private organizations to assure a statewide system of care is in place for Children with Special Health Care Needs. Interagency agreements with Vocational Rehabilitation assures early linkages to facilitate transition services for young adults. The Dept. of Social Services as well as Department of Disabilities and Special Needs participate in the Transition Focus Group organized and staffed by CRS. Numerous other State Agencies, as well as parents, are participating in the Measuring and Monitoring Grant Steering Committee to identify ways to measure the six National Outcome Objectives for CSHCN. Local CRS staff serve as members of BabyNet (Part C of IDEA) Local Children's Councils to ensure that coordination among agencies occurs for BabyNet eligible children birth to three years of age. Local CRS staff also meet on a monthly basis with staff from Department of Disabilities and Special needs, Department of Social Services, Department of Mental Health, and others to ensure that services are coordinated.

CRS has taken the lead to bring agencies together to develop a data warehouse to 1) Identify the number of Children with Special Health Care Needs in the state, 2) assess duplication and gaps in services across agencies, and, 3) Determine the number of children with special health care needs with a medical home. The ways in which the data warehouse can be utilized to construct a more seamless service system for Children with Special Health Care needs in the state are numerous. Agencies included in the data warehouse at the present time include 1) DHEC-CRS and Part C, 2) Department of Disabilities and Special Needs, 3) Department of Vocational Rehabilitation, 4) Medicaid State Agency and 5) School for the Deaf and Blind and 6) Department of Mental Health. Future plans are to include the Departments of Education, Alcohol and Drug Abuse, and the Continuum of Care.

To assure a services system is in place, CRS allocates funding to the thirteen Health Districts for the operation of CRS Clinics. Presently CRS operates 100 clinics per month. Also CRS develops partnerships with the physician community to either provide services or assure that services are available. Health components of community based systems of care are coordinated through partnerships. A partnership with Shiners Hospital in Greenville has, for many years, assisted the smooth transition to local services to ensure that these children receive the services they need when they are released from the hospital back to the community. CRS also funds several parent organizations in the state to provide parent support. Partnerships have been developed with tertiary centers as well as private physicians throughout the State. These partnerships outstation CRS staff in tertiary centers and physicians offices to assure coordination of care as children transition to local services in the community. Thirty such partnerships exist at this time. Treatment plans are developed on each child with the family to identify services the child needs, as well as to identify the service provider. This enhances assurances that health care components are being coordinated in a manner that maximizes the best use of community resources and payment sources.

Collaboration

South Carolina has a number of opportunities for input from the public and private sector as well as consumers relative to the needs assessment process. There are over 100 partnerships between the local health departments and private/governmental entities promoting medical homes and sub-specialty services for children and Children with Special Health Care Needs. Ongoing input is available through the partnerships relative to the needs of the providers as well as the consumers. These local partnerships are centralized at two monthly statewide meetings designed to work with the state Medicaid Agency and the State Medical Association. There are also several task forces that meet regularly with a goal of seeking input relative to the needs of the MCH population. These groups include the Commissioner's Pediatric Task Force, the OB Task Force, the Family Medicine Advisory Committee, and the Medical Advisory for Children with Special Health Care Needs. In addition to ongoing customer satisfaction surveys conducted locally and on a statewide basis, input is provided relative to the needs of Children with Special Health Care Needs by Family Connections, the statewide ICC, and the Parent Involvement group.

Program Monitoring and Evaluation

DHEC is committed to a continuous Quality Control/Quality Improvement (CQI) process. All of our program areas

have representatives on a agency-wide committee. The Children's Rehabilitative Services staff and its co-workers in other divisions are developing a CQI tool for monitoring how services are delivered in our state. We have a Family Planning monitoring tool, and are in the process of conducting a statewide assessment evaluation of family planning services. Each of South Carolina's 13 health districts is involved in ongoing self-study activities structured around the MCH planning cycle. The Bureau of Epidemiology's Maternal and Child Health Division provides consultation and support on an ongoing basis for health risk assessment, program monitoring, and the evaluation of MCH-related health initiatives.

Summary

A growing emphasis on prevention, health promotion and disease management with a population focus changes the expectation of the health department's role in a community. The challenges faced are complex, multi-disciplinary in nature with uncertain answers. All agencies must evaluate and set priorities to address a growing disparate population. The health department will be a leader in developing new and innovative approaches as well as formulating policy to protect the health of the Maternal and Child Health populations. Community infrastructure building and partnerships must occur to meet the gaps in our system. Political leaders and key stakeholders must put emphasis on and channel funds to meet the health care needs of the citizens. Value for a Healthy Community will occur as community leaders come together to address concerns together.

The "ideal role" is one with a continuum of health care which would allow the different agencies to focus on their areas of expertise with a smooth referral process from one entity to another to ensure improved patient outcomes. Elimination of costly duplication is a necessity for all health care providers. All players on equal footing with equal buy in and equal standards. The common goal would be improved patient outcomes based on identified population needs. Unfortunately some of the advocacy roles of public health lack an identified funding source. In the ideal world, public health values would be embraced by key legislators who hold the key to funding for many health department functions.

The state's population has been changing demographically and culturally for some time. Consequently, so has the need to assure the provision of health services in a culturally competent environment for all citizens. The system continues to be challenged by no or inadequate access to health care services for citizens who have adequate health insurance as well as those who do not.

For detailed reports from the five Needs Assessment population workgroups, please see Appendix G.

3.2 Health Status Indicators

See SD forms 5.4 through 5.7 under the supporting documents section.

3.2.1 Priority Needs

Direct Health Care Services

With respect to direct health care services, we are aware that too few providers of primary, specialty, and sub-specialty care exist in the rural areas of the State. As public health staff transitions out of the role of providing direct health care services, further collaboration is necessary with the private sector providers. This will allow the public health staff to direct its attention to identifying gaps in services, quality of care issues, evaluation of public health initiatives, and other core public health functions.

Enabling Services

Transportation is a major obstacle for large segments of the Maternal and Child Heath populations. Inadequate or unavailable transportation prevents access to necessary health care services, and these needs must be addressed. Addressing transportation will increase access to risk-appropriate quality health care for women, infants, and children in the state including Children with Special Health Care Needs.

Population-Based Services

Children and adolescents in South Carolina rank high relative to peers in other states with respect to obesity and poor nutrition. Efforts should be directed to improving the nutritional status of women, infants, children and Children with Special Health Care Needs.

Injuries are the highest cause of death among children over the age of one. We in public health need to take steps to carefully monitor injury rates especially with respect to motor vehicle crashes, to identify problem areas in the state and reduce injuries overall.

Substance abuse is a major problem among children and teenagers in South Carolina. The YRBS has indicated that more than half of teenagers have used alcohol or illegal substances. Continuing efforts need to be taken to reduce the prevalence of drug and alcohol use among children and teenagers.

Approximately 46% of births are reported to be unintended in South Carolina. A reduction in unintended pregnancies would most likely be associated with improvements in birth outcomes, perinatal health, school readiness, food security and general well being.

Newborn home visits provide an important venue that establishes a connection between new families and the

healthcare delivery system. The purpose of these visits is to assess the infant for potential health problems, assess the home environment for potential safety concerns, and offer education and support to the parents on issues such as feeding, bathing and other needs and questions the parents may have.

Infrastructure Development

The challenges posed by the preparation of this five year Comprehensive Needs Assessment underscore the need for strengthened collaboration with other agencies and data managers. Strengthening of these links will result in further refinements of program evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, systems of care and information systems.

South Carolina is working hard to make substantial improvement in the health status of the various MCH populations. Following is a list of the 10 state priority needs that resulted from the 5-year needs assessment process described above. Please note that several changes have been made to the previous priority list to reflect the work coming out of the 5-year needs assessment. These priorities address issues related to **pregnant women**, **reproductive aged women and infants** (#s 1,2,3,5,6,7,8); to **children and adolescents** (#s 1,2,4,5,6,9), and, **children with special health care needs** (#s 1,2,4,5,9,10). These priority needs are also included on form SD 14.1 in the Supporting Documents Section (5.8).

- 1. Increase access to quality risk appropriate care for women, infants and children, including CSHCN.
- 2. Improve the nutritional status of women, infants and children, including CSHCN.
- 3. Increase access to preconceptional and interconceptional care.
- 4. Reduce preventable injuries in the state among the MCH populations.
- 5. Increase access for women, infants, children, including CSHCN, to enabling, family support services.
- 6. Decrease the use of illegal and legal substances among the MCH populations.
- 7. Increase access to newborn home visits.
- 8. Reduce the percentage of births reported to be unintended.
- 9. Improve the quality and availability of health and health education services in school settings.
- 10. Ensure that there is a transitional program in place statewide for CSHCN, for those children aging out of the program.

3.3 Annual Budget and Budget Justification

3.3.1 Completion of Budget Forms

See SD forms # 2.1, 3.1, 4.1 and 4.2, and 5.1 and 5.2 under the Supporting Document Section (5.8)

3.3.2 Other Requirements Maintenance of Effort

Methodology

The 1989 Maintenance of Effort was based on the state expenditure of \$8,425,466 by the DHEC Bureau of Maternal and Child Health.

FY 94 was the first year the direct state appropriation for MCH services to the Bureau dropped below the 1989 effort level. The expenditures for FY 94 were \$8,114,682. Therefore, we requested that the 1989 baseline be amended to include expenditures for family planning services. The FY 89 family planning expenditures were \$3,020,500.

Identification of Maintenance Effort

The State of South Carolina documents a total of \$11,445,966 as the 1989 baseline against which future effort is measured. This combines the 1989 state expenditures for maternal and child health services, including family planning.

For FY 2001, state appropriations for the Bureau of Maternal and Child Health Divisions of Women and Children's Services, and Children's Rehabilitative Services are expected to be \$7,996,694 (this figure will increase slightly before the beginning of SFY 2001 due to reappropriations).

Therefore, the total maintenance of effort for FY 2001 is \$ 14,437,461 calculated by combining the state appropriated dollars for maternity, child health and CRS programs of \$7,996,694 with the state appropriated dollars for family planning of \$6,440,767. The State of South Carolina exceeds the 1989 maintenance of effort requirement by \$2,991,495.

Match

Title V matching requirements for the FY 2000 grant award of \$11,972,698 (including carry forward funding from FY 1999 of \$1,369,501) is \$10,006,649. We identify the state allocation of \$7,996,684 to the Divisions of Women and Children's Services (maternity, child health), and Children's with Special Health Care Needs (CRS), as match. In addition, we also identify \$11,820,299 in state appropriated dollars to the counties for MCH programs as the remainder of funds needed for matching Title V.

Fiscal Management Procedures

Division of Finance fiscal management procedures were provided in the FY 1995 MCH Title V Grant Application. Another copy can be provided upon request.

"30-30 Minimum"

As required by OBRA '89, South Carolina allocates a minimum of 30% of Federal Block Grant Funds for preventive and primary care services to children, and a minimum of 30% is allocated to children with special health care needs that are part of a system of services which promotes family-centered, community based coordinated care.

Fair Method of Allocating Grant Funds

See Appendix B for a description of the method used by South Carolina for allocating its MCH and CRS funds to the public health districts.

3.4 Performance Measures

Immediately following are figure 2 (Core Public Health Services Delivered by MCH Agencies) and figure 3 (Title V, Performance Measurement System). Please refer to them when reviewing figure 4 (Performance Measures Summary Sheet) and when reviewing the Annual Plan (Section IV) for each performance measure.

Figure 2

CORE PUBLIC HEALTH SERVICES DELIVERED BY MCH AGENCIES



Examples:
Basic Health Services,
and Health Services for CSHCN

ENABLING SERVICES:

Examples:

Transportation, Translation, Outreach, Respite Care, Health Education, Family Support Services, Purchase of Health Insurance, Case Management, Coordination with Medicaid, WIC, and Education

POPULATION-BASED SERVICES:

Examples:

Newborn Screening, Lead Screening, Immunization,
Sudden Infant Death Syndrome Counseling, Oral Health,
Injury Prevention, Nutrition
and Outreach/Public Education

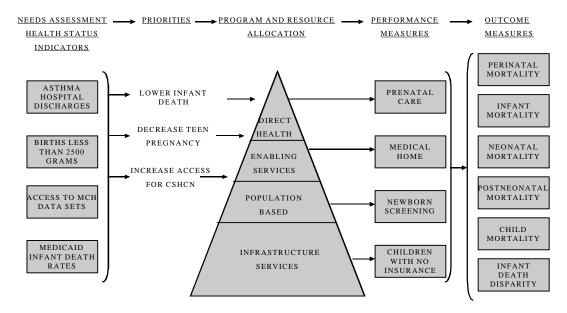
INFRASTRUCTURE BUILDING SERVICES:

Examples:

Needs Assessment, Evaluation, Planning, Policy Development, Coordination, Quality Assurance, Standards Development, Monitoring, Training, Applied Research, Systems of Care, and Information Systems

MCHB/DSCH 10/20/97

Figure 3
TITLE V BLOCK GRANT
PERFORMANCE MEASUREMENT SYSTEM



3.4.1 National "Core" Five Year Performance Measures

Following is figure 4, which describes by level and type of service, the 18 "Core" performance measures, and the 9 State "Negotiated" performance measures.

FIGURE 4 PERFORMANCE MEASURES SUMMARY SHEET

	Pyrar	Pyramid Level of Service				Type of Service			
Performance Measure	DH		P	I	С	P	R		
	С	Е	В	В			F		
		S	S						
1) The percent of State SSI beneficiaries less than 16 years old	X								
receiving rehabilitative services from the State Children with					X				
Special Health Care Needs (CSHCN) Program.		-			 				
2) The degree to which the State Children with Special Health	X				37				
Care Needs (CSHCN) Program provides or pays for specialty and subspecialty services, including care coordination, not					X				
otherwise accessible or affordable to its clients.									
3) The percent of Children with Special Health Care Needs									
(CSHCN) in the State who have a "medical/health home"		X			X				
4) Percent of newborns in the State with at least one screening		1	X				X		
for each of PKU, hypothyroidism, galactosemia,									
hemoglobinopathies (e.g. the sickle cell diseases) (combined).									
5) Percent of children through age 2 who have completed			X				X		
immunizations for Measles, Mumps, Rubella, Polio,									
Diphtheria, Tetanus, Pertussis, Haemophilus Influenza,									
Hepatitis B.									
6) The birth rate (per 1,000) for teenagers aged 15 through 17			X				X		
years.									
7) Percent of third grade children who have received			X				X		
protective sealants on at least one permanent molar tooth.									
8) The rate of deaths to children aged 0-14 caused by motor			X				X		
vehicle crashes per 100,000 children.									
9) Percentage of mothers who breastfeed their infants at			X				X		
hospital discharge.				-	<u> </u>				
10) Percentage of newborns who have been screened for			X				X		
hearing impairment before hospital discharge.			1	-	<u> </u>				
11) Percent of Children with Special Health Care Needs									
(CSHCN) in the State CSHCN program with a source of				X	X				
insurance for primary and specialty care.		_	1	-	-				
12) Percent of children without health insurance.				37	37				
				X	X				

	Pyramid Level of Service				Type of Service		
Performance Measure	DH		P	I	С	P	R
	С	Е	В	В			F
		S	S				
13) Percent of potentially Medicaid eligible children who have							
received a service paid by the Medicaid Program				X		X	
14) The degree to which the State assures family participation							
in program and policy activities in the State CSHCN program				X		X	
15) Percent of very low birth weight live births							X
				X			
16) The rate (per 100,000) of suicide deaths among youths							X
15-19				X			
17) Percent of very low birth weight infants delivered at							X
facilities for high-risk deliveries and neonates				X			
18) Percent of infants born to pregnant women receiving							X
prenatal care beginning in the first trimester				X			

NOTE: DHC = Direct Health Care ES = Enabling Services PBS = Population Based Services IB = Infrastructure Building C = Capacity P = Process RF = Risk Factor

	Pyramid Level of Service				Type of Service			
Negotiated Performance Measures	DH C	Е	P B	I B	С	P	R F	
		S	S					
1) Percent of Medicaid newborns in the state receiving a home visit	X						X	
2) Percent of women giving birth with an unintended pregnancy			X				X	
3) Percent of counties that have a formal partnership with their local school district(s) which includes assuring access to a medical home and age appropriate health education services for school children			X		X			
4) Percent of Districts with an injury prevention program in place			X		X			
5) The degree to which the State assures a transition is developed for those children aging out of the State CSHCN program				X	X			
6) Percent of high school students who smoke			X				X	
7) Percent of counties with obstetrical partnerships that include ensuring access to risk appropriate and quality care				X	X			

	Pyramid Level of Service				Type of Service			
Negotiated Performance Measures	DH		P	I		P	R	
	С	Е	В	В	C		F	
		S	S					
8) Ratio of overweight/obese children to overweight/obese pre pregnant, breastfeeding and postpartum women in the WIC program			X				X	
9) Percent of counties with a pre and interconceptional health promotion program in place			X		X			

NOTE: DHC = Direct Health Care ES = Enabling Services PBS = Population Based Services IB = Infrastructure Building C = Capacity P = Process RF = Risk Factor

3.4.1.1 Five Year Performance Objectives

See SD #11 in the Supporting Documents Section (5.8) for the Annual and Five-year performance objectives for each performance measure.

3.4.2 State "Negotiated" Five Year Performance Measures

3.4.2.1 Development of State Performance Measures

The development of the state performance measures for 2001 benefitted directly from the work that went into the 5-year needs assessment. Similar to past efforts, a consultative process involving key MCH staff was used to determine priorities and state performance measures. At the April, 2000 MCH Team meeting, the 5-year needs assessment workgroup leaders presented their summary findings and recommendations for their respective populations. Through an open but structured decision-making process, the 10 state draft priorities were determined at that time. Subsequent MCH Bureau discussions finalized the priorities (see priority listing above).

With the priority listing, MCH Bureau staff then took the state priorities and in coordination with the various programs, developed the state performance measures. The "Core" performance measures were also reviewed carefully to ensure that the State measures were complementary and developed to fill in gaps that the Core measures did not address. See SD #16, Section 5.10 for detail sheets on each State performance measure.

Due to the more in-depth and comprehensive nature of this year's needs assessment process, several of the state performance measures have been changed for 2001, to better address the identified needs of the various MCH

populations. Four of the measures are new for this year, and three others have been improved in terms of specificity and content. It is our hope that the priorities themselves will not change substantially over the next several years, but the negotiated performance measures may evolve as baseline data is obtained and other data becomes more precise and specific. South Carolina is only submitting nine state measures for this coming year, although one priority area, access to enabling services, has not been addressed directly. The state will work to develop this priority into a performance measure for next year's Title V application.

We recognize that the 27 combined measures are only representative of the many interventions and programs being done in South Carolina, but they do represent key indicators that reflect the overall health status and well being of the various MCH populations.

3.4.2.2 Discussion of State Performance Measures

Following are the 9 State Performance Measures, with an explanation of why each was chosen, and its particular relationship to the priority needs and the outcome measures:

State Performance Measure #1: Percent of Medicaid newborns in the state receiving a home visit. This measure is a Direct Health Care Service, and it is classified as a Risk Factor measure. This measure is a carry over from last year, but has been modified. The measure now looks at all Medicaid newborns receiving a home visit, regardless of who provides the service. Last year the measure looked at the proportion of Medicaid newborns receiving a DHEC home visit only. Although new born home visits are an increasing priority for DHEC, we also have an assurance responsibility to facilitate post partum new born home visits regardless of who the provider is. Home visits in South Carolina have been associated with improved postneonatal outcomes. Home visits contain counseling components related to behavior change and the linking of mothers and infants to providers and services. The ultimate goal is to have all newborns in the state receive a new born home visit, but South Carolina is beginning its focus on the Medicaid population because it can be measured, and due to the higher prevalence of risk factors associated with poor health outcomes in this population. This measure is directly related to the priority need of increasing access to newborn home visits, and related to increasing access to enabling, family support services, reducing preventable injuries, and increasing access to quality risk-appropriate care. This measure is related to the neonatal, postneonatal, and infant mortality outcome measures.

State Performance Measure #2: Percent of women giving birth with an unintended pregnancy. This measure is a Population Based Health Care Service and is classified as a Risk Factor measure. Unintendedness

is associated with poorer birth outcomes and greater risk behaviors by the mother. Almost one-half of South Carolina's births are reportedly unintended. This measure is directly related to the priority need of reducing the percentage of births in the State reported to be unintended and is a carryover measure from last year. This measure is related to the following outcome measures: neonatal, perinatal, postneonatal, infant mortality and reducing the ratio between the Black and White infant mortality rates.

State Performance Measure #3: Percent of counties that have a formal partnership with their local school district(s) which includes assuring access to a medical home and age appropriate health education services for school children. This measure is a Population Based Health Care Service, and is classified as a Capacity measure. This measure has been modified from last year, which at that time focused primarily on school nurse issues. The measure now looks at partnership links between DHEC and the local schools, with an overall emphasis on linkages with the private medical community and increasing health education efforts in the schools. Access to a medical home and health education services are important components of child well-being. This measure is directly related to the priority need of improving the quality and availability of health and health education services in school settings. This measure is related to the child mortality outcome measure.

State Performance Measure #4: Percent of Districts with an injury prevention program in place. This measure is a Population Based Health Care measure, and is classified as a Capacity measure. This measure has been modified from last year's application, to include intentional injuries and other MCH populations in addition to children. Although injuries are the number one killer of children in South Carolina, districts are being encouraged to look at other populations including infants and pregnant women. This measure is directly related to the priority need of reducing preventable injuries in the state. The measure is related to the reducing childhood mortality outcome measure.

State Performance Measure #5: The degree to which the State assures a transition is developed for those children aging out of the State CSHCN program. This measure is an Infrastructure Building Service, and is classified as a Process measure. Transition for CSHCN aging out of the program is an essential assurance role for the Program. This measure has been carried over from last year. This measure is directly related to the priority need of ensuring that there is a transitional program in place statewide for CSHCN. This measure is indirectly related to reducing the childhood mortality outcome measure.

State Performance Measure #6: Percent of high school students who smoke. This measure is a Population Based Health Care Service, and is classified as a Risk Factor measure. Smoking trends in the teen population are increasing, and smoking is associated with other risky behaviors. With the tobacco settlement discussions in-state,

smoking prevention is receiving increased attention, and we hope resources to help combat the problem. This measure is related to the priority need of decreasing the use of illegal and legal substances among the MCH populations in the state. The measure is related to the infant, neonatal, perinatal and postneonatal mortality outcome measures.

State Performance Measure #7: Percent of counties with obstetrical partnerships that include ensuring access to risk appropriate and quality care. This measure is a Infrastructure Based Service and is classified as a Capacity measure. Over the last several years, there has been a substantial shift in the provider makeup of prenatal care in the state. DHEC used to provide prenatal care services statewide, but now only provides these services in nine out of forty-six counties, with the private medical community now providing the great majority of prenatal care. DHEC has a role and responsibility however, to provide enabling services in partnership with the medical community, and to assure that risk appropriate care is being provided, regardless of payment source. This measure is related to the priority need of increasing access to quality risk appropriate care for women, infants and children, including CSHCN, in the state. The measure is associated with the infant, neonatal, perinatal, postneonatal mortality outcome measures, and in the rate ratio in the IMR outcome measure as well.

State Performance Measure #8: Ratio of overweight/obese children to overweight/obese pre pregnant, breastfeeding and postpartum women in the WIC program. This measure is a Population Based Health Care Service and is classified as a Risk Factor measure. Childhood obesity is emerging as a state and national problem that will have profound public health consequences as overweight children become overweight adults. The state is beginning to focus more attention on health promotion related to obesity, and a legislatively commissioned report on obesity has just been released. This measure is related to the priority need to improve the nutritional status of women, infants and children. This measure is indirectly related to the child mortality performance measure.

State Performance Measure #9: Percent of counties with a pre and interconceptional health promotion program in place. This measure is a Population Based Service, and is classified as a Capacity measure. Access to effective interconceptional and preconceptional services can have an impact on birth outcomes. Emphasis of this measure is on smoking, folic acid, and alcohol. For this first year, data for this measure will be obtained from district self-reports. This measure is related to the priority need of increasing access to preconceptional and interconceptional care. This measure is directly related to the infant, neonatal, perinatal, and postneonatal outcome measures, and the ratio in the white and black infant mortality rates outcome measure as well.

3.4.2.3 Five Year Performance Objectives

See SD #11 in the Supporting Documents Section (5.8) for the Annual and Five-year performance objectives for each performance measure.

3.4.2.4 Review of State Performance Measures

Nothing to report.

3.4.3 Outcome Measures

See SD #12 in Supporting Documents (5.8) for 5-year objectives for the Outcome Measures. South Carolina at this time has not developed an additional outcome measure to monitor.

IV. REQUIREMENTS FOR THE ANNUAL PLAN

4.1 Program Activities Related to Performance Measures

The capacity and resource capability of the Title V program in South Carolina is described in Sections 1.5.1.2 and 1.5.1.3. A description of the relationship between the State performance measures and the South Carolina priority needs can be found in Section 3.4.2.2.

15 of the 18 Core performance measures coincide closely with the State priority needs or represent areas that the State considers important and which are being addressed already:

- For **pregnant women**, **reproductive aged women and infants** these are: newborn screening, immunizations in two year olds, breastfeeding of infants, newborn hearing screening, percentage of all deliveries that are VLBW, VLBWs delivered at Level IIIs, and first trimester entry into prenatal care.
- For **children and adolescents** core measures that fit the above criteria are: births to teens, children without health insurance, motor vehicle fatalities, and Medicaid children receiving services.
- C For **children with special health care needs** priority measures are: specialty and subspecialty services, medical homes for CSHCN, insurance coverage, and family participation.

Two CORE measures that have not been considered as great of a priority are SSI beneficiaries and the State CSHCN program, and suicide in teens. There is a well defined coordination system between the State CSHCN program and SSDI, and with Medicaid expansion in the state, it is possible that the percentage of SSI beneficiaries that receive services from the State CSHCN program will decrease over the medium term. The program will monitor closely this percentage however. Mental health outreach has traditionally been considered more within the scope of other social services agencies in the state, but with this measure, DHEC will begin to identify the activities that are ongoing and

planned, and facilitate improved coordination with the other social services agencies that also work with youth. An internal adolescent health taskforce for Health Services included mental health issues among its recommendations that the agency will need to address in close partnership with the Department of Mental Health and DAODAS.

South Carolina recognizes that dental sealants are an important preventive, public health intervention (CORE measure #7). DHEC has not had an Office of Public Health Dentistry in over ten years, but that will soon change. The agency has successfully concluded negotiations with HRSA that will result in a Public Health Service Dentist (the Coordinator) being assigned to the state for at least two years to begin to coordinate public oral health activities. One of the Coordinators first tasks will be to design and implement a needs assessment. This assessment will enable the state to more accurately measure the prevalence of sealants and dental caries, and to help determine what priorities the Coordinator should focus on.

PLAN FOR MEETING EACH PERFORMANCE MEASURE, BY LEVEL OF SERVICE AND BY POPULATION (note: Federal and State Measures are co-mingled here)

Following are summary descriptions of activities and plans for next year that South Carolina will implement to reach the specified objectives(s). The plan is organized by the four levels of the pyramid, and under each level, by the three MCH populations.

Level 1: Direct Health Care Services

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

- 1) The percent of State SSI beneficiaries less than 16 years old receiving rehabilitative services from the State Children with Special Health Care Needs (CSHCN) Program. (FPM #1). South Carolina has set a target for next year of 31 percent of SSI beneficiaries less than 16 years old receiving a CRS rehabilitative service. In those instances where services are not covered by Title XIX there are procedures in place to approve services in the same manner of the CSHCN program. However, with the expansion of Medicaid in South Carolina, these requests have diminished. Recipients of SSI are also referred to DDSN, School for the Deaf and Blind, Department of Mental Health, and HIV programs; all of these referrals are through a MOA with all institutions.
- 2) The degree to which the State Children with Special Health Care Needs (CSHCN) Program provides or pays for specialty and subspecialty services, including care coordination, not otherwise accessible or affordable to its clients. (FPM #2). South Carolina will maintain this next year the presently provided or paid for eight services described in SD#11 (Section 5.8). Specialty care is available around the state via the system of CRS clinics and through

six tertiary level hospitals and two proximate out- of-state centers (Charlotte and the Medical College of Georgia in Augusta). CRS funds community-based care by operating local clinics throughout the State. Specialized multi-disciplinary clinics are made available as close as possible to the home county of the child. Physicians from the Medical University of Charleston travel to Greenville, Spartanburg, and Columbia to hold clinics, as well as hold regular clinics at Level III Medical Centers. The concept of the specialist traveling to the community has been expanded to Metabolic, Endocrine and Hematology clinics. The primary and routine health care needs of these children are assessed in clinics and followed up through development of services plans and coordination of care. CRS clinics are staffed across disciplines and subspecialties.

CHILDREN

1) **Percent of Medicaid newborns in the state receiving a home visit.** (SPM #1). This measure has been modified for FY 2001. We will now be monitoring all newborns of Medicaid mothers and whether they received a home visit, not just those receiving a home visit from a DHEC provider. South Carolina plans on increasing the percent of Medicaid newborns receiving a home visit to 72 percent in 2000, 75 percent in 2001, and 78 percent in 2002. We are committed to improving our reporting system to more accurately measure our efforts. The Promising Practices committee of the Governor's First Steps initiative (school readiness program for under 6 year olds), has proposed that all newborns receive a home visit, regardless of insurance coverage. Healthy Families is another initiative that will promote, as a best practice, the inclusion of a newborn post partum home visit for all newborns. This initiative is being piloted in five counties, and priority is being given to first time parents. Over time the goal will be to include all newborns/mothers.

Level 2: Enabling Health Care Services

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

1) The percent of Children with Special Health Care Needs (CSHCN) in the State who have a "medical/health home." (FPM #3). For this measure, the term Medical Home and Primary Care Provider are used synonymously. The target for next year is to increase to 92 percent the number of children in the CRS program with a primary care provider. Children are assessed at each visit to assure the availability of a primary care provider. There is also a Treatment Plan for every child which is revised and updated annually. Assessment of the primary care status is assessed even for those families who are followed infrequently, or who have failed to keep appointments. All staff members, across disciplines, are prepared to assist families in obtaining a primary care provider. A current list of providers is maintained in every clinic. For those families who face transportation problems or other barriers to care, a referral to Family Support Services will provide them with in-depth assistance. Efforts have been in place statewide to improve partnerships with private providers such as pediatricians, sub-specialists, hospitals, universities and children's clinics. South Carolina

has some kind of private-public partnership in every health district. Six of the 13 health districts reported that over 90 percent of their CSHCN clients had a medical home.

PREGNANT WOMEN AND INFANTS

None to report.

CHILDREN

None to report.

Level 3: Population Based Health Care Services

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

None to report.

PREGNANT WOMEN AND INFANTS

1) Percent of newborns in the State with at least one screening for each of PKU, hypothyroidism, galactosemia, hemoglobinopathies (e.g., the sickle cell diseases) (combined) (FPM #4). The maintenance target for next year is for 99% of all children to be screened for the described conditions. All hospitals provide this service by law, and health department personnel follow-up closely all positive results. See SD #6 under Supporting Documents (5.8) for numbers tested, and follow-up initiated.

2) Percentage of mothers who breastfeed their infants at hospital discharge. (FPM #9).

WIC Population: In order to achieve the goal of 37 percent next year (from almost 34 percent), breastfeeding promotion and support will continue to be provided as part of the South Carolina WIC Program. Local health districts will designate one staff person as breastfeeding coordinator who will coordinate breastfeeding promotion and support activities in that district in order to encourage increases in breastfeeding initiation and duration rates. Breastfeeding peer counselors will personally work with WIC clients to encourage and support their decision to breastfeed. Continued breastfeeding follow-up support will also be provided as needed. Task appropriate breastfeeding education will be provided for WIC health professionals who counsel either prenatal clients, breastfeeding women or breastfeed infants to assure that updated and correct breastfeeding education is being provided to clients.

Public Health: Newborn home visits by a nurse, lactation consultant, breastfeeding peer counselor and/or other health care professional will be provided for eligible clients. Due to these follow-up home visits breastfeeding difficulties may be prevented and/or eliminated thus preventing mothers from weaning their infants from the breast prematurely. Breastfeeding support provided during home visits will encourage increases in South Carolina breastfeeding duration

rates among breastfeeding mothers and their breastfed infants.

Community: Through six regional breastfeeding coalitions (Aiken, Low Country, Midlands, Pee Dee, Piedmont & Trident) as well as the South Carolina Breastfeeding Coalition, which consists of members from both private and public health sections, activities will be implemented in the community promoting and supporting the act and science of breastfeeding as the superior form of infant nutrition. Through education, publicity, recommendation and person-to-person support, the coalition(s) will be instrumental in fomenting social change throughout the state. Breastfeeding initiation as well as duration will increase among mothers who breastfeed their infants at hospital discharge.

- 3) Percentage of newborns who have been screened for hearing impairment before hospital discharge. (FPM #10). South Carolina hopes to implement universal newborn hearing screening by the end of 2001. The target for 2000 is for 60 percent (from 38 percent in 1999) of all occurrent births receiving a hearing screening. Legislation is pending and we are expecting to receive the funding that will enable South Carolina to achieve full implementation by the end of 2001.
- 4) **Percent of women giving birth with an unintended pregnancy. (SPM #2)**. In 1998, about 46 percent of all births were unintended according to the statewide PRAMS survey, the lowest recorded amount. The target for next year is to reduce to 44.0 percent the number of pregnancies that are reportedly unintended. All groups of women experience unintended pregnancy. A higher percentage of unintended pregnancies occur in women younger than 20 years of age, not married, Black, Medicaid eligible, and with less than 12 years of education.

Local health departments provide family planning services. There are 93 sites statewide. Currently 24 of those sites have extended hours or weekend hours to provide services for those who cannot be seen during the routine hours of 8:30 to 5 PM. Many health departments have integrated service delivery which facilitates meeting the customers needs for family planning services. Others have worked to keep a two week waiting times for appointments, prioritized services for teens and post partum women, and utilized outreach workers to follow up on missed appointments as well as do case finding in local communities. DHEC has contracted with the University of South Carolina to conduct a statewide family planning consumer survey. The purpose of the survey is to assist us in better directing our program efforts. Questions to be asked include what are barriers to care, and are women receiving the services they want. The result of the survey will assist us in better targeting our outreach efforts to get reproductive aged women into family planning services.

5) Percent of counties with a pre and interconceptional health promotion program in place. (SPM#9).

19 of the 46 counties in the state (42 percent) reported a score of at least "1" related to always screening reproductive aged women for risk behaviors related to alcohol and cigarette consumption and folic acid intake. The target for next year is to increase this percentage to 50 percent of counties always screening reproductive aged women. South Carolina

recognizes the priority that must be given to interconceptional and preconceptional health of women, if we are to more strongly impact negative pregnancy outcomes. This initial measure will be modified over time to more precisely describe the scope of services being provided at the county level. Some counties are conducting promotional and educational programs around pre and interconceptional health, but not risk screening women one-on-one, and other counties are more effective on the individual level, but doing little community awareness work.

CHILDREN

- 1) Percent of children at age 2 who have completed immunizations for Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, Hepatitis B.(FPM #5). South Carolina continues to achieve very high levels of immunization in its two year old population. The latest (Spring 1999) population survey indicated that 89 percent of two year olds were fully immunized. The target for next year is to maintain at least a 90 percent level through interventions that sustain the ongoing success that the state is having. The five interrelated strategies are to:
 - enhance the quality and quantity of vaccination delivery services (through increasing access to immunization in DHEC and non-DHEC clinic and provider sites) and through training for all immunization providers in the state
 - C reduce vaccine costs for parents
 - C increase community participation, education, and partnerships
 - C improve the monitoring of disease and vaccination coverage
 - C improve vaccines and vaccine use
- 2) The birth rate (per 1,000) for teenagers aged 15 through 17 years. (FPM #6). South Carolina has one of the highest teen birth rates in the country. The birth rate for the 15-17 year old age group has decreased consistently since 1995 (41.9) to 1998 (38.7), with Black teenagers having slightly less than twice the rate than that for White teens. This gap appears to be relatively consistent, although more recent trends are encouraging. For the next reporting period (1999) South Carolina has a goal of 38 births per 1,000 teens.

The abstinence program (under Title V) has been implemented in South Carolina, and has been promoting abstinence until marriage among teens and young adults in the state. DHEC is providing technical assistance to the Governor's Office in this effort.

Health Department clinic services for this group varies. All health departments offer family planning services during routine work hours. Twenty-three of 90+ sites offer extended week day or weekend clinics to accommodate teens. Those areas of the state with institutes of higher learning have partnered with the colleges health services to delivery family planning services at the college or university.

Future efforts include partnerships with local schools and school nurses, implementing "easy access" systems for teens that include increasing the number of sites that have extended service hours for teens.

- 3) Percent of third grade children who have received protective sealants on at least one permanent molar tooth.
- (FPM #7). The target for next year is for 45 percent of third graders to have a protective sealant on at least one permanent molar, although this measure continues to not be measurable with any degree of certitude in South Carolina. The public oral health landscape in the state, however, is changing, and in time this measure and oral public health in general in the state will be on firmer ground. South Carolina has successfully concluded negotiations with HRSA that will result in a Public Health Service dentist coming to the state in 2000 for at least two years, to serve as the State Dental Coordinator. One of the immediate tasks for the Dental Coordinator will be to coordinate a statewide oral health needs assessment that will include sealant prevalence. Medicaid increased reimbursement in 2000 to the 75 percentile for dental procedures, and over 200 new dentists have enrolled with the Medicaid dental program. All Districts are working with dental providers in their communities to form partnerships and to provide enabling services for missed appointments and for education follow-up. Collaboration with the dental school is taking place through a HRSA funded dental sealant project. The CDC has also funded an oral health in the schools grant that has received strong support from DHEC. This grant will be working to improve oral health curriculum in the schools and to improve access to dental services by school aged children.
- 4) The rate of deaths to children aged 0-14 caused by motor vehicle crashes per 100,000 children. (FPM #8). The definition of this measure has changed and now includes infants as well as children 1-14 years old. DHEC has set a target of no more than 6.8 fatalities for every 100,000 infants/children next reporting period. Child passenger safety training is provided to district staff and community groups to increase the safe transport of children. Staff participate in safety seat check-ups and buckle-up events in the community which provide a forum to educate parents and demonstrate the correct use of safety seats and the need for seat belt use. Bicycle safety education is also provided to children and there parents, as well as free bicycle helmets. DHEC staff utilizes media, special events and partnerships with various community organizations to educate the public regarding safe transport of children and adults. South Carolina plans to use information gained from Child Fatality Review Committees statewide to determine possible suggestions and strategies for prevention interventions. We are currently working to secure funds to implement a booster seat program in the districts.
- 5) Percent of counties that have a formal partnership with their local school district(s) which includes assuring access to a medical home and age appropriate health education services for school children (SPM#3).

This measure is replacing SPM #13 (nurse to student ratio). In 1999, 28 of the 46 counties (61 percent) reported having some form of a formal partnerships with a local school district (some counties have more than one school district). The

target for next year is for 65 percent of counties to report having a formal agreement. Linkages between schools, school nurses, school children and their parents, and primary care and enabling service providers are essential components of successful primary care programs for children. School districts in South Carolina are autonomous so by necessity this effort will be incremental and piecemeal, but the state is committed these linkages in the service system. Increasing the number of nurses at the state level will continue to be a priority as well.

6) The state has a childhood injury prevention program in place. (SPM #4). This measure has been modified from last year, through including more than one MCH population and intentional injuries as other key components of an injury prevention program. The target for next year is for all districts (13/13 or 100 percent) to report that their injury prevention programs is in place, with the expanded definitions. This is a substantial increase, but appears reachable as most districts only need to incorporate intentional injury prevention to their activities, and have indicated they plan on doing so. DHEC provides educational information to the public regarding poisoning, drowning, fire safety and other injury causes. Fire safety educational materials are provided to clients through the Post-Partum New Born Visit Program. Homes without smoke detectors are being provided one as part of the visit in six counties in the state. Public awareness highlighting the injury problem is conducted through media outlets and participation in community events, such as health fairs. DHEC will also take advantage of events opportunistically to address the major causes of childhood injury. South Carolina plans to use information gained from Child Fatality Review Committees statewide to determine possible suggestions and strategies for prevention interventions.

7) Percent of high school students who smoke (SPM#6).

The target for next year is to reduce the percentage of teens who smoke to 34 percent (from 36 percent last year). DHEC, through the South Carolina Tobacco Control Program (SCTCP) conducts outcome-based activities statewide directed at the following four program goals: prevent initiation to the use of tobacco products; promote quitting; eliminate exposure to secondhand smoke; and identify and eliminate health disparities between populations. SCTCP funds 12 local coalitions that work with schools and youth groups on tobacco-use prevention education and activities. In addition, SCTCP provides funds to the SC Department of Education's Healthy Schools Program, which is currently assessing training and technical assistance needs related to tobacco-use prevention in public schools.

SCTCP works with schools to assess smoke-free policies and policy enforcement and supports 17 teams of teens to attend the tobacco track of the week long Teen Institute during the summer and return to their communities with seed money and action plans to conduct peer counseling and educational programs. SCTCP coalitions furnish adult volunteers for the annual Youth Access Survey. In the coming year, SCTCP will assess possibilities for school-based cessation programs and will conduct the state Youth Tobacco Survey.

8) Ratio of overweight/obese children to overweight/obese pre pregnant, breastfeeding and postpartum women in the WIC program (SPM#8). In August 1999, DHEC established the SC Advisory Committee on Obesity. The Committee prepared a report containing a description of the obesity problem in the state, approaches to prevention and management of obesity in children and adults, and research currently being conducted in South Carolina. This report will be used to recommend strategic goals related to obesity for inclusion in the DHEC strategic plan, in the Health Services operational plan, and here in the Title V plan for the agency. Efforts are now underway to develop a coordinated and comprehensive statewide initiative to impact the high rates of childhood and adult obesity, and to reduce the obesity-related costs of health care in South Carolina. The rate ratio (children to adult women) is now 11.7, and the target for next year is to reduce this difference to 11 times greater.

Level 4: Infrastructure Building Services

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

- 1) Percent of Children with Special Health Care Needs (CSHCN) in the State CSHCN Program with a source of insurance for primary and specialty care. (FPM #11). See the description of activities under FPM #12 (percent of children without health insurance), under Infrastructure Building Services, Children. The State CSHCN Program is actively involved with public health district staff in implementing the expansion of the Medicaid program up to 150 percent of poverty, which affects this measure directly. The target for 2000 (next reporting period) is to increase to 92 percent the number of CSHCN with health insurance.
- 2) The degree to which the State assures family participation in program and policy activities in the State CSHCN Program. (FPM #14). The goal for this measure this next year is to increase by one point (to 17 on a 1-18 scale) the degree of involvement in the program and to work on increasing the participation of families in the Program over the next 5 years. One CRS Parent Advisory Council member from each district is employed part time (16-20 hours per week) in all of the district CRS Clinics. Their title is Parent Resource Specialists. We provided our first training for the Parent Resource Specialists and will continue to provide training as needed. They call families to schedule appointments, assess needs and make follow up calls on missed appointments. In clinic they provide parent support, information, resources, referral and advocacy for families.
- 3) The degree to which the State assures a transition is developed for those children aging out of the State CSHCN program. (SPM #5). The SC State CSHCN Program to date has partially met this goal through the development of: transition closure criteria (see state performance measure #5); the formation of a transition focus group that is in the process of developing transition outcomes and interventions; collaboration with the Kentucky Commission for CSHCN in the development of transition information and strategies; and a joint effort between the Parent Advisory Council and

the transition focus group to develop information needed by families. The Transition Focus Group has also been instrumental in acquiring a module that addresses the transition needs of children with hemophilia. This module is being modified to accommodate the needs of children with Sickle Cell Disease. The state transition coordinator also maintains a productive relationship with SC Vocational Rehabilitation (SCVR) to assure implementation of memoranda of agreement between SCVR and the SC CSHCN program. The SC State CSHCN Program plans to achieve a "11" on the transitional scale this next year and a "12" by the year 2003 when the system is fully implemented.

PREGNANT WOMEN AND INFANTS

1) **Percent of very low birth weight live births (FPM #15)**. The State target for 1999 (next reporting period) is to decrease to 1.7 percent of all births as VLBWs. Overall, the state's very low weight births as an annual percentage of total births has remained constant since 1992.

Most of the health districts focus on activities that promote access to prenatal care, risk assessment and utilization of supplemental foods (WIC). Several districts have Fetal and Infant Mortality Review teams and utilize information gained from that process to correct systems issues that impact this measure. There is collaboration with Healthy Start projects in selected areas throughout the state as well as the Regional Perinatal Boards and March of Dimes Community Task Forces.

District activities planned for the future include increasing participation in preconceptual health activities, i.e. risk assessment, smoking cessation, education regarding STD and vaginal/cervical infections (see SPM#9). This also includes provider education related to screening for STD's etc. during pregnancy as well as appropriate treatment. Program consultant staff will offer districts technical assistance regarding contributing factors to very low birth weight births and successful strategies for interventions.

2) Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates. (FPM #17). South Carolina has been experiencing a decrease in the percentage of very low birth weight infants being delivered in Level III hospitals, with the most recent figure in 1998 showing 69.8 percent. The target for 1999 (next reporting period) is 74 percent. A number of factors are responsible for the decrease and include an increased number of neonatologists practicing in the state, and reimbursement systems which are not supportive of delivery in risk-appropriate setting. At the state level, public health is focusing on the issue and identifying strategies to increase the percent of VLBW births delivered in Level III hospitals. During 2001, DHEC will work with payers to develop strategies for providing financial incentives for providers to participate in the risk-appropriate care system; review and revise, as needed, hospital regulations to increase compliance; and lead educational activities directed towards physicians, consumers and hospitals on SC's system of risk-appropriate care and improved outcomes related to delivery

of VLBW babies in Level III hospitals. At the District level, mechanisms for working with the designated Regional System Developer to monitor access to risk-appropriate care and promote early identification and referral of high-risk pregnant women are operational. All districts are represented on their respective Regional Perinatal Boards which provide leadership in assuring a system of risk-appropriate care through assessment, system development and promotion of health initiatives. These activities will continue along with monitoring of community systems and support for activities initiated at the state level. As a result of the combined efforts at the state and district levels, SC projects to reverse the decline and begin to show a slight upward trend. By 2000 we hope to have 75% of VLBW births delivered in Level III hospitals.

- 3) Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester. (FPM #18). In 1998, 82.6% of all women entered care in the first trimester of pregnancy. For 1999 the target is 85.0, and for 2000 it is 87.0 percent. There has been a gradual, yet consistent improvement in first trimester entry into care since 1989. This trend is seen among Whites as well as Blacks and Others. This is a multifaceted problem and requires work on several fronts. This includes accurate reporting on prenatal care entry on the birth certificates, physicians promoting first visits at twelve weeks gestation and thirdly, information to women of childbearing age regarding the importance of early entry into care. The health districts work regularly with the Regional Systems Developers, hospital vital record clerks, hospital medical records and physicians offices to monitor the quality of data reported on birth certificates. They also have initiated and/or participated in partnerships with private providers for district service with complementing Family Support Services, March of Dimes Task Forces, Prenatal Mission, Healthy Start and others to implement strategies that will positively access care and improve 1st trimester entry. There has been work on the State level through the Governor's MICH Council and the Medical Association to work with providers as well as working with the USC College of Anthropology to improve our understanding of the customers we serve. The plans are frequently assessed and new strategies implemented and have included implementation of "Babies and You" and the Think Ahead program as well as articles for local papers.
- 4) Percent of counties with obstetrical partnerships that include ensuring access to risk appropriate and quality care (SPM#7). In 1999, 26/46 counties (57 percent) reported having a formal partnership agreement with obstetrical providers in their counties. For 2000 the target is to increase to 60 percent of counties reporting having a formal agreement in place. South Carolina has transitioned the bulk of prenatal care to the private sector (prenatal care is now being provided by DHEC in only 9 of the 46 counties). Despite this transition, first trimester entry and adequacy of prenatal care have increased, a tribute to the partnership effort led by the health department. DHEC continues to have an essential core public health role of assurance of care, in terms of access and quality. The provision of enabling services will provide necessary support to the prenatal effort in the state. This measure over time will be modified as we more precisely determine what are the necessary components in successful obstetrical partnerships.

CHILDREN

- 1) **Percent of children without health insurance**. (**FPM #12**). The target for both 2000 and 2001 is for 13 percent of under 18 year olds to be uninsured (based on CPS estimates for the under 200 percent of poverty population). We hope that these numbers will then continue to decline further. From September 1997 to date, over 113,000 children were enrolled in Medicaid (net gain). Of these more than half were eligible for Medicaid under SCHIP and the rest under the old income criteria of Medicaid. Every Health District is actively involved with SCHIP enrollment, and reporting outreach efforts to Medicaid via the Mega Contract s. All Health Districts are actively distributing SCHIP applications through clinical services, and through community and home based activities. At present SCHIP in South Carolina covers uninsured children up to 150 percent of poverty. Legislative discussions are taking place at this time that may result in a Medicaid expansion to 165 percent of poverty for children.
- 2) Percent of potentially Medicaid eligible children who have received a service paid by the Medicaid Program. (FPM #13). South Carolina is placing tremendous effort on increasing Medicaid enrollment through the states SCHIP initiative. As more children become enrolled, they will be receiving services through the Medicaid program. For 2000 (next reporting period) the target is 88 percent of potentially Medicaid eligible children receiving a paid for Medicaid service, and for 2001 the target is 90 percent. All 13 health districts continue to emphasize private/public partnerships for medical homes for children. In 1993, efforts began with four model partnerships. Currently there are 100 partnerships for medical homes for children in 36 of 46 counties. Even with the increasing number of partnerships, there is still a need to continue to provide comprehensive well child care in our county health departments. All 13 health districts still provide EPSDT services, as well as some services to uninsured clients.
- 3) The rate (per 100,000) of suicide deaths among youths 15-19. (FPM #15). The suicide rate since 1992 has been very unstable, going from a high of 13.0 in 1993 to a low of 6.2 in 1997. The data indicates that within this population, more White males are at risk of suicide than any other group. For reporting period 1999 the target is 7.8, for 2000 it is 7.5 and for 2001, it is 7.2 per 100,000 youth.

Local health department staff are involved in various ongoing and planned prevention activities that address suicide and aimed at reducing the risk of suicide among youth. Those activities include partnerships, collaboration and coordination with local service agencies including substance abuse treatment centers, community mental health centers, local schools, to family violence service agencies and other community entities serving youth. Activities range from depression and risk assessment when providing direct services, receiving training on appropriate intervention skills to providing training on suicide risk factors to teachers, community groups and other health care professionals. Other activities include providing workshop sessions to adolescents in the schools on topics such as stress management, self-esteem, anger management, coping strategies, and entrepreneurial training. Our agency social work department

developed a suicide protocol to assist in guiding social work staff in providing services to individuals assessed to be at risk of suicide. All social work staff are trained in Risk Assessment and Duty to Warn. Other locally planned activities include promotion of a "Youth Hotline Calling Card" with local support agency numbers, educational programs for summer youth events, and provision of life skills training. Some local efforts plan to address those most at risk, males ages 15-19.

4.2 Other Program Activities

NON-DUPLICATION OF MEDICAID PAYMENTS TO SSI RECIPIENTS UNDER 16

In S.C., services to children under 16 who are receiving Supplemental Security Income are administered by the state Title V program for CSHCN. The program is known as the Supplemental Security Income/Disabled Children's Program (SSI/DCP). Since the enactment of the block grant, the program has been integrated into the community-based services of the CSHCN program. Approximately 3,762 children are served. Services to children receiving SSI consist primarily of case management services. In those instances where services are not covered by Title XIX there are procedures in place to approve services in the same manner of the CSHCN program. However, with the expansion of Medicaid in South Carolina, these requests have diminished. Recipients of SSI are also referred to DDSN, School for the Deaf and Blind, Department of Mental Health, and HIV programs; all of these referrals are through a MOA with all institutions.

TOLL-FREE TELEPHONE NUMBERS

South Carolina operates two toll-free telephone numbers targeting the access of health services by mothers and children. **First**, the "Care Line" (1-800-868-0404) is a statewide advocacy service for families experiencing difficulty in accessing prenatal care, family planning, infant and child health care, and services for CSHCN or other related services for themselves or their families. This hotline became operational in October 1989. Since it's inception, over 70,000 families have been assisted. USDA support through WIC has been instrumental in ensuring the success of the Care Line.

The Care Line number is advertised through posters, brochures, flyers, television, newspapers, and postage-paid information postcards. In some areas of the state, the number has been advertised on milk cartons, grocery bags, and in monthly utility bills. The Care Line's target includes:

- (1) Women needing information and/or assistance in obtaining care (such as getting an appointment with a Title V or XIX provider, how/where to apply for Medicaid, or transportation problems getting to health care);
- (2) Children needing health care and related services (such as how/where to apply for WIC or where to go for immunizations);
- (3) Families of CSHCN. The position of CRS Parent Liaison/Careline Advocate was born out of the need for parents

of CSHCN to have a parent advocate as well as a toll free phone number for access to that advocate.

The Care Line is staffed Monday through Friday from 8:30 a.m. to 5:00 p.m. by six trained contract advocates who respond to needs and concerns of the caller. An answering service handles calls during the nights and weekends. Staff for the hotline maintain files on Title V and Title XIX providers of prenatal and infant care and Title X family planning and specialty and other providers (CSHCN) throughout the state. One hotline staff person designated as the "Information Resource Coordinator" researches and updates files on a broad range of health and human service resources for mothers and children in S.C.

Care Line callers are referred to the appropriate health care or other service providers. Some callers experience barriers to care that they cannot resolve on their own. For these people, a system has been created to provide advocacy to "broker" for them through difficult systems and get them the needed help. Advocacy and "problem calls" are followed-up to ensure resolution of problems. The hotline is an interagency partnership between DHEC, the Governor's Office infant mortality project -- "Caring for Tomorrow's Children" and "My Baby's Keepsake Book", and the S.C. March of Dimes.

The **second** toll-free telephone number (1-800-922-1107) is targeted to persons with disabilities including families of infants and toddlers with disabilities and is known as the BabyNet Central Directory. It is a required component of Part C of IDEA. Trained consultants provide callers with local services and resources through an electronic database. The BabyNet Central Directory is a component of the South Carolina Services Information System (SCSIS) operated by the Center for Developmental Disabilities at the University of South Carolina School of Medicine. The directory provides information on resources available in the state (therapies, financial, assistive technology, transportation, support groups, and advocacy organizations) and providers available in the state (speech/language pathologists, special education professionals, audiologists, developmental pediatricians, and therapists).

EPSDT COORDINATION AND STANDARDS

Assurance is provided that South Carolina coordinates activities between MCH and the EPSDT Program under Title XIX. DHEC has a contract to provide EPSDT services to eligible clients. EPSDT provides comprehensive and preventive health services to Medicaid eligible children from birth to age 21. Diagnostic and treatment services will be provided for defects found during screenings. The Division of Women and Children's Services provides approximately 40% (1996) of all EPSDT screenings in the state. Other providers include private physicians offices, federally qualified health centers and hospital outpatient clinics. In situations where Public Health clinics do not provide the screenings, they are available through private public partnership to provide the traditional public health supportive services to complement the medical care. In South Carolina, Medicaid eligibility is contracted by the Title XIX Agency to the Department of Social Services (DSS). DSS is responsible for eligibility but a simplified application

has been developed for "mail in" as a result of the SCHIP expansion. The Division of Women and Children's Services is responsible, through contract with Title XIX, for providing outreach education to all new eligibles so that the family is aware of the services to which the child is entitled. Public health nurses provide the education and assist the families in securing a medical home for the children. Once the children are in a medical home, public health staff, at the local level, continues to support the providers and clients to assure adherence to the medical plan outlined by the primary EPSDT provider.

The EPSDT Program in South Carolina follows the periodicity schedule recommended by the American Academy of Pediatrics. The Division of Women and Children's Services was actively involved in the selection of this schedule and was instrumental in providing input into the current content of EPSDT screenings. Social work and nutritional services are available, as needed, by EPSDT clients.

MEDICAID APPLICANT IDENTIFICATION ASSISTANCE

Assurance is provided that DHEC does coordinate with the Title XIX Agency - S.C. Department of Health and Human Services (DHHS) in providing funding, assisting in the eligibility process and the provision of services to Pregnant Women, and Infants and Children in the State. South Carolina offers Medicaid to Pregnant Women and Infants up to 185% of poverty and Children ages 1 through age 18 up to 150% of poverty (with the latest SCHIP expansion). South Carolina began Medicaid expansion in October, 1987, and has continued to expand coverage. DHEC uses a number of different approaches to identify and assist Medicaid eligible pregnant women and infants. As indicated below, our methods include coordination with other agencies as well as the private sector.

DHEC central office, DHHS and DSS began outstationing "OCWI" (optional coverage for women, infants and children) workers prior to the OBRA '89 requirements. These contracts are a prime example of a cooperative effort between state agencies designed to break down the barriers to Medicaid eligibility for the state's population. DHEC continues to contract with DHHS/DSS and subsidizes 35 Medicaid Eligibility workers outstationed in our health departments. Even though DSS has Medicaid Eligibility workers in all of their 46 county offices, DHEC encourages agreements between DSS county offices and DHEC county health departments in any county that presumes increased Medicaid participation by providing on-site OCWI workers in the health department. These workers cover 42 sites in 27 counties. The Health Department and OCWI staff work with patients to schedule one day service whenever possible. Women can come in for their initial prenatal exam and apply for Medicaid in one visit. Workers also refer patients for other needed services, such as WIC, TANF, housing, etc.

Through the Medicaid "Mega" Services contract, paraprofessionals are utilized along with professional staff to work in recruiting potentially eligible individuals into the Medicaid program. Outstationed workers continue to assist with the eligibility process for reproductive aged women.

WIC income guidelines are revised at the same time as Medicaid income guidelines to ensure a coordinated process in identifying those who are Medicaid eligible. When WIC clients are identified as being eligible, appointments are made with the outstationed Medicaid eligibility workers or the County Department of Social Services Office, whichever is applicable. State agencies and the private sector continue to work cooperatively toward the goal of eliminating barriers to Medicaid eligibility which spans the continuum from client identification, assistance with eligibility documentation requirements, eligibility processing at the clinic site, meeting transportation needs, etc., through the process of providing appropriate care or case management.

4.3 Public Input

Responsibilities for the public review process lie with DHEC. A public hearing on this application is scheduled for July 19, 2000. Comments and revisions to this application stemming from the public hearing will be forwarded to the MCHB and Region IV as appropriate. A copy of the application will be available for public review 30 days prior to the hearing. Newspaper advertisements announcing the hearing time, site and location of applications for review will be placed statewide.

Citizens who attend the hearing will be afforded the opportunity to speak. Issues and/or concerns which cannot be resolved at the public hearing will be forwarded to the Commissioner of Health. DHEC will study the issues and then forwards a written response to the originator of the issue to assure final resolution. At this point in time, the application will either remain the same or be amended to include changes.

SC DHEC's Maternal and Child Health Bureau also uses other methods to obtain policy, programmatic and planning input from the public, including maintaining extensive contact with public and private organizations and individuals throughout the state.

4.4 Technical Assistance

See SD #15 (Section 5.8) for specific information on Technical Assistance needs of South Carolina.

V. SUPPORTING DOCUMENTS

5.1 Glossary

GLOSSARY

Adequate prenatal care - Prenatal care were the observed to expected prenatal visits is greater than or equal to 80% (the Kotelchuck Index).

Administration of Title V Funds - The amount of funds the State uses for the management of the Title V allocation. It is limited by statute to 10 percent of the Federal Title V allotment.

Assessment - (see "Needs Assessment")

Capacity - Program capacity includes delivery systems, workforce, policies, and support systems (e.g., training, research, technical assistance, and information systems) and other infrastructure needed to maintain service delivery and policy making activities. Program capacity results measure the strength of the human and material resources necessary to meet public health obligations. As program capacity sets the stage for other activities, program capacity results are closely related to the results for process, health outcome, and risk factors. Program capacity results should answer the question, "What does the State need to achieve the results we want?"

Capacity Objectives - Objectives that describe an improvement in the ability of the program to deliver services or affect the delivery of services.

Care Coordination Services for Children With Special Health Care Needs (CSHCN, see definition below) - those services that promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special health care needs and their families. [Title V Sec. 501(b)(3)]

Carryover (as used in Forms 2 and 3) - The unobligated balance from the previous years MCH Block Grant Federal Allocation.

Case Management Services - For pregnant women - those services that assure access to quality prenatal, delivery and postpartum care. For infants up to age one - those services that assure access to quality preventive and primary care services. (Title V Sec. 501(b)(4)

Children -A child from 1st birthday through the 21st year, who is not otherwise included in any other class of individuals.

Children With Special Health Care Needs (CSHCN) - (For budgetary purposes) Infants or children from birth through the 21st year with special health care needs who the State has elected to provide with services funded through Title V. CSHCN are children who have health problems requiring more than routine and basic care including children with or at risk of disabilities, chronic illnesses and conditions and health-related education and behavioral problems. (For planning and systems development) - Those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Children With Special Health Care Needs (CSHCN) - Constructs of a Service System

- 1. State Program Collaboration with Other State Agencies and Private Organizations. States establish and maintain ongoing interagency collaborative processes for the assessment of needs with respect to the development of community-based systems of services for CSHCN. State programs collaborate with other agencies and organizations in the formulation of coordinated policies, standards, data collection and analysis, financing of services, and program monitoring to assure comprehensive, coordinated services for CSHCN and their families.
- 2. **State Support for Communities**. State programs emphasize the development of community-based programs by establishing and maintaining a process for facilitating community systems building through mechanisms such as technical assistance and consultation, education and training, common data protocols, and financial resources for communities engaged in systems development to assure that the unique needs of CSHCN are met.
- 3. Coordination of Health Components of Community-Based Systems. A mechanism exists in communities across the State for coordination of health services with one another. This includes coordination among providers of primary care, habilitative and rehabilitative services, other specialty medical treatment services, mental health services, and home health care.
- 4. Coordination of Health Services with Other Services at the Community Level. A mechanism exists in communities across the State for coordination and service integration among programs serving CSHCN, including early intervention and special education, social services, and family support services.

Classes of Individuals - authorized persons to be served with Title V funds. See individual definitions under "Pregnant

Women," "Infants," "Children with Special Health Care Needs," "Children," and "Others."

Community - a group of individuals living as a smaller social unit within the confines of a larger one due to common geographic boundaries, cultural identity, a common work environment, common interests, etc.

Community-based Care - services provided within the context of a defined community.

Community-based Service System - an organized network of services that are grounded in a plan developed by a community and that is based upon needs assessments.

Coordination (see Care Coordination Services)

Culturally Sensitive - the recognition and understanding that different cultures may have different concepts and practices with regard to health care; the respect of those differences and the development of approaches to health care with those differences in mind.

Culturally Competent - the ability to provide services to clients that honor different cultural beliefs, interpersonal styles, attitudes and behaviors and the use of multicultural staff in the policy development, administration and provision of those services.

Deliveries - women who received a medical care procedure (were provided prenatal, delivery or postpartum care) associated with the delivery or expulsion of a live birth or fetal death.

Direct Health Care Services - those services generally delivered one-on-one between a health professional and a patient in an office, clinic or emergency room which may include primary care physicians, registered dietitians, public health or visiting nurses, nurses certified for obstetric and pediatric primary care, medical social workers, nutritionists, dentists, sub-specialty physicians who serve children with special health care needs, audiologists, occupational therapists, physical therapists, speech and language therapists, specialty registered dietitians. Basic services include what most consider ordinary medical care, inpatient and outpatient medical services, allied health services, drugs, laboratory testing, x-ray services, dental care, and pharmaceutical products and services. State Title V programs support - by directly operating programs or by funding local providers - services such as prenatal care, child health including immunizations and treatment or referrals, school health and family planning. For CSHCN, these services include specialty and subspecialty care for those with HIV/AIDS, hemophilia, birth defects, chronic illness, and other conditions requiring sophisticated technology, access to highly trained specialists, or an array of services not generally available

in most communities.

Enabling Services - Services that allow or provide for access to and the derivation of benefits from, the array of basic health care services and include such things as transportation, translation services, outreach, respite care, health education, family support services, purchase of health insurance, case management, coordination of with Medicaid, WIC and educations. These services are especially required for the low income, disadvantaged, geographically or culturally isolated, and those with special and complicated health needs. For many of these individuals, the enabling services are essential - for without them access is not possible. Enabling services most commonly provided by agencies for CSHCN include transportation, care coordination, translation services, home visiting, and family outreach. Family support activities include parent support groups, family training workshops, advocacy, nutrition and social work.

EPSDT - Early and Periodic Screening, Diagnosis and Treatment - a program for medical assistance recipients under the age of 21, including those who are parents. The program has a Medical Protocol and Periodicity Schedule for well-child screening that provides for regular health check-ups, vision/hearing/dental screenings, immunizations and treatment for health problems.

Family-centered Care - a system or philosophy of care that incorporates the family as an integral component of the health care system.

Federal (Allocation) (as it applies specifically to the Application Face Sheet [SF 424] and Forms 2 and 3) -The monies provided to the States under the Federal Title V Block Grant in any given year.

Government Performance and Results Act (GPRA) - Federal legislation enacted in 1993 that requires Federal agencies to develop strategic plans, prepare annual plans setting performance goals, and report annually on actual performance.

Health Care System - the entirety of the agencies, services, and providers involved or potentially involved in the health care of community members and the interactions among those agencies, services and providers.

Infants - Children under one year of age not included in any other class of individuals.

Infrastructure Building Services - The services that are the base of the MCH pyramid of health services and form its foundation are activities directed at improving and maintaining the health status of all women and children by providing support for development and maintenance of comprehensive health services systems including development and

maintenance of health services standards/guidelines, training, data and planning systems. Examples include needs assessment, evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, information systems and systems of care. In the development of systems of care it should be assured that the systems are family centered, community based and culturally competent.

Jurisdictions - As used in the Maternal and Child Health block grant program: the District of Columbia, the Commonwealth of Puerto Rico, the Virgin Islands, Guam, American Samoa, the Commonwealth of the Northern Mariana Islands, the Republic of the Marshal Islands, the Federated States of Micronesia and the Republic of Palau.

Kotelchuck Index - An indicator of the adequacy of prenatal care. See Adequate Prenatal Care.

Local Funding (as used in Forms 2 and 3) - Those monies deriving from local jurisdictions within the State that are used for MCH program activities.

Low Income - an individual or family with an income determined to be below the income official poverty line defined by the Office of Management and Budget and revised annually in accordance with section 673(2) of the Omnibus Budget Reconciliation Act of 1981.[Title V, Sec. 501 (b)(2)]

MCH Pyramid of Health Services - (see "Types of Services")

Measures - (see "Performance Measures")

Needs Assessment - a study undertaken to determine the service requirements within a jurisdiction. For maternal and child health purposes, the study is to aimed at determining: 1) What is essential in terms of the provision of health services; 2) What is available; and, 3) What is missing

Objectives - The yardsticks by which an agency can measure its efforts to accomplish a goal. (See also "Performance Objectives")

Other Federal Funds (Forms 2 and 3) - Federal funds other than the Title V Block Grant that are under the control of the person responsible for administration of the Title V program. These may include, but are not limited to: WIC, EMSC, Healthy Start, SPRANS, HIV/AIDs monies, CISS funds, MCH targeted funds from CDC and MCH Education funds.

Others (as in Forms 4, 7, and 10) - Women of childbearing age, over age 21, and any others defined by the State and not otherwise included in any of the other listed classes of individuals.

Outcome Objectives - Objectives that describe the eventual result sought, the target date, the target population, and the desired level of achievement for the result. Outcome objectives are related to health outcome and are usually expressed in terms of morbidity and mortality

Outcome Measure - The ultimate focus and desired result of any set of public health program activities and interventions is an improved health outcome. Morbidity and mortality statistics are indicators of achievement of health outcome. Health outcomes results are usually longer term and tied to the ultimate program goal. Outcome measures should answer the question, "Why does the State do our program?"

Performance Indicator - The statistical or quantitative value that expresses the result of a performance objective.

Performance Measure - a narrative statement that describes a specific maternal and child health need, or requirement, that, when successfully addressed, will lead to, or will assist in leading to, a specific health outcome within a community or jurisdiction and generally within a specified time frame. (Example: "The rate of women in [State] who receive early prenatal care in 19__." This performance measure will assist in leading to [the health outcome measure of] reducing the rate of infant mortality in the State).

Performance Measurement - The collection of data on, recording of, or tabulation of results or achievements, usually for comparing with a benchmark.

Performance Objectives - A statement of intention with which actual achievement and results can be measured and compared. Performance objective statements clearly describe what is to be achieved, when it is to be achieved, the extent of the achievement, and target populations.

Population Based Services - Preventive interventions and personal health services, developed and available for the entire MCH population of the State rather than for individuals in a one-on-one situation. Disease prevention, health promotion, and statewide outreach are major components. Common among these services are newborn screening, lead screening, immunization, Sudden Infant Death Syndrome counseling, oral health, injury prevention, nutrition and outreach/public education. These services are generally available whether the mother or child receives care in the private or public system, in a rural clinic or an HMO, and whether insured or not.

PRAMS - Pregnancy Risk Assessment Monitoring System - a surveillance project of the Centers for Disease Control and Prevention (CDC) and State health departments to collect State- specific, population-based data on maternal attitudes and experiences prior to, during, and immediately following pregnancy.

Pregnant Woman - A female from the time that she conceives to 60 days after birth, delivery, or expulsion of fetus.

Preventive Services - activities aimed at reducing the incidence of health problems or disease prevalence in the community, or the personal risk factors for such diseases or conditions.

Primary Care - the provision of comprehensive personal health services that include health maintenance and preventive services, initial assessment of health problems, treatment of uncomplicated and diagnosed chronic health problems, and the overall management of an individual's or family's health care services.

Process - Process results are indicators of activities, methods, and interventions that support the achievement of outcomes (e.g., improved health status or reduction in risk factors). A focus on process results can lead to an understanding of how practices and procedures can be improved to reach successful outcomes. Process results are a mechanism for review and accountability, and as such, tend to be shorter term than results focused on health outcomes or risk factors. The utility of process results often depends on the strength of the relationship between the process and the outcome. Process results should answer the question, "Why should this process be undertaken and measured (i.e., what is its relationship to achievement of a health outcome or risk factor result)?"

Process Objectives - The objectives for activities and interventions that drive the achievement of higher-level objectives.

Program Income (as used in the Application Face Sheet [SF 424] and Forms 2 and 3) - Funds collected by State MCH agencies from sources generated by the State's MCH program to include insurance payments, MEDICAID reimbursements, HMO payments, etc.

Risk Factor Objectives - Objectives that describe an improvement in risk factors (usually behavioral or physiological) that cause morbidity and mortality.

Risk Factors - Public health activities and programs that focus on reduction of scientifically established direct causes of, and contributors to, morbidity and mortality (i.e., risk factors) are essential steps toward achieving health outcomes. Changes in behavior or physiological conditions are the indicators of achievement of risk factor results. Results focused

on risk factors tend to be intermediate term. Risk factor results should answer the question, "Why should the State address this risk factor (i.e., what health outcome will this result support)?"

State - as used in this guidance, includes the 50 States and the 9 jurisdictions. (See also, Jurisdictions)

State Funds (as used in Forms 2 and 3) - The State's required matching funds (including overmatch) in any given year.

Systems Development - activities involving the creation or enhancement of organizational infrastructures at the community level for the delivery of health services and other needed ancillary services to individuals in the community by improving the service capacity of health care service providers.

Technical Assistance (TA) - the process of providing recipients with expert assistance of specific health related or administrative services that include; systems review planning, policy options analysis, coordination coalition building/training, data system development, needs assessment, performance indicators, health care reform wrap around services, CSHCN program development/evaluation, public health managed care quality standards development, public and private interagency integration and, identification of core public health issues.

Title XIX, number of infants entitled to - The unduplicated count of infants who were eligible for the State's Title XIX (MEDICAID) program at any time during the reporting period.

Title XIX, number of pregnant women entitled to - The number of pregnant women who delivered during the reporting period who were eligible for the State's Title XIX (MEDICAID) program

Title V, number of deliveries to pregnant women served under - Unduplicated number of deliveries to pregnant women who were provided prenatal, delivery, or post-partum services through the Title V program during the reporting period.

Title V, number of infants enrolled under - The unduplicated count of infants provided a direct service by the State's Title V program during the reporting period.

Total MCH Funding - All the MCH funds administered by a State MCH program which is made up of the sum of the Federal Title V Block grant allocation, the Applicant's funds (carryover from the previous year's MCH Block Grant allocation - the unobligated balance), the State funds (the total matching funds for the Title V allocation - match and overmatch), Local funds (total of MCH dedicated funds from local jurisdictions within the state), Other federal funds

(monies <u>other</u> than the Title V Block Grant that are under the control of the person responsible for administration of the Title V program), and Program Income (those collected by state MCH agencies from insurance payments, MEDICAID, HMO's, etc.).

Types of Services - The major kinds or levels of health care services covered under Title V activities. See individual definitions under "Infrastructure Building", "Population Based Services", "Enabling Services" and "Direct Medical Services".

YRBS - Youth Risk Behavior Survey - A national school-based survey conducted annually by CDC and State health departments to assess the prevalence of health risk behaviors among high school students.

5.2 Assurances and Certifications

ASSURANCES -- NON-CONSTRUCTION PROGRAMS

Note: Certain of these assurances may not be applicable to your project or program. If you have any questions, please contact the Awarding Agency. Further, certain federal assistance awarding agencies may require applicants to certify to additional assurances. If such is the case, you will be notified.

As the duly authorized representative of the applicant I certify that the applicant:

- 1. Has the legal authority to apply for Federal assistance, and the institutional, managerial and financial capability (including funds sufficient to pay the non-Federal share of project costs) to ensure proper planning, management and completion of the project described in this application.
- 2. Will give the awarding agency, the Comptroller General of the United States, and if appropriate, the State, through any authorized representative, access to and the right to examine all records, books, papers, or documents related to the assistance; and will establish a proper accounting system in accordance with generally accepted accounting standards or agency directives.
- 3. Will establish safeguards to prohibit employees from using their position for a purpose that constitutes or presents the appearance of personal or organizational conflict of interest, or personal gain.
- 4. Will initiate and complete the work within the applicable time frame after receipt of approval of the awarding agency.
- 5. Will comply with the Intergovernmental Personnel Act of 1970 (42 U.S.C. Sects. 4728-2763) relating to prescribed standards for merit systems for programs funded under one of the nineteen statutes or regulations specified in Appendix A of OPM's Standards for a Merit System of Personnel Administration (5 C.F.R. 900, Subpart F).
- 6. Will comply with all Federal statutes relating to non-discrimination. These include but are not limited to (a) Title VI of the Civil Rights Act of 1964 (P.L. 88 Sect. 352) which prohibits discrimination on the basis of race, color or national origin; (b) Title IX of the Education Amendments of 1972, as amended (20 U.S.C. Sects. 1681-1683, and 1685-1686), which prohibits discrimination on the basis of sex; (c) Section 504 of the Rehabilitation Act of 1973, as amended (29 U.S.C. Sect. 794), which prohibits discrimination on the basis of handicaps; (d) The Age Discrimination Act of

1975, as amended (42 U.S.C. Sects 6101 6107), which prohibits discrimination on the basis of age; (e) the Drug Abuse Office of Treatment Act of 1972 (P.L. 92-255), as amended, relating to non-discrimination on the basis of drug abuse; (f) the Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and Rehabilitation Act of 1970 (P.L. 91-616), as amended, relating to non-discrimination on the basis of alcohol abuse or alcoholism; (g) Sects. 523 and 527 of the Public Health Service Act of 1912 (42 U.S.C. Sect. 3601 et seq.), as amended, relating to non-discrimination in the sale, rental, or financing of housing; (i) any other non-discrimination provisions in the specific statute(s) under which application for Federal assistance is being made; and (j) the requirements of any other non-discrimination statute(s) which may apply to the application.

- 7. Will comply, or has already complied, with the requirements of Titles II and III of the Uniform Relocation Assistance and Real Property Acquisition Policies Act of 1970 (P.L. 91-646) which provide for fair and equitable treatment of persons displaced or whose property is acquired as a result of Federal or federally assisted programs. These requirements apply to all interests in real property acquired for project purposes regardless of Federal participation in purchases.
- 8. Will comply with the provisions of the Hatch Act (5 U.S.C. Sects 1501-1508 and 7324-7328) which limit the political activities of employees whose principal employment activities are funded in whole or in part with Federal funds.
- 9. Will comply, as applicable, with the provisions of the Davis-Bacon Act (40 U.S.C. Sects. 276a to 276a-7), the Copeland Act (40 U.S.C. Sect 276c and 18 U.S.C. Sect. 874), the Contract Work Hours and Safety Standards Act (40 U.S.C. Sects. 327-333), regarding labor standards for federally assisted construction subagreements.
- 10. Will comply, if applicable, with flood insurance purchase requirements of Section 102(a) of the Flood Disaster Protection Act of 1973 (P.L. 93-234) which requires recipients in a special flood hazard area to participate in the program and to purchase flood insurance if the total cost of insurable construction and acquisition is \$10,000 or more.
- 11. Will comply with environmental standards which may be prescribed pursuant to the following: (a) institution of environmental quality control measures under the National Environmental Policy Act of 1969 (P.L. 91-190) and Executive Order (EO) 11514; (b) notification of violating facilities pursuant to EO 11738; (c) protection of wetlands pursuant to EO 11990; (d) evaluation of flood hazards in flood plains in accordance with EO 11988; (e) assurance of project consistency with the approved State management program developed under the Coastal Zone Management Act of 1972 (16 U.S.C. Sects. 1451 et seq.); (f) conformity of Federal actions to State (Clear Air) Implementation Plans under Section 176(c) of the Clear Air Act of 1955, as amended (42 U.S.C. 7401 et seq.); (g) protection of underground sources of drinking water under the Safe Drinking Water Act of 1974, as amended, (P.L. 93-523); and (h) protection

of endangered species under the Endangered Species Act of 1973, as amended, (P.L. 93-205).

- 12. Will comply with the Wild and Scenic Rivers Act of 1968 (16 U.S.C. Sects 1271 et seq.) related to protecting components or potential components of the national wild and scenic rivers systems.
- 13. Will assist the awarding agency in assuring compliance with Section 106 of the National Historic Preservation Act of 1966, as amended (16 U.S.C. Sect. 470), EO 11593 (identification and preservation of historic properties), and the Archaeological and Historic Preservation Act of 1974 (16 U.S.C. Sects. 469a-1 et seq.)
- 14. Will comply with P.L.93-348 regarding the protection of human subjects involved in research, development, and related activities supported by this award of assistance.
- 15. Will comply with Laboratory Animal Welfare Act of 1966 (P.L. 89-544, as amended, 7 U.S.C. 2131 et seq.) pertaining to the care, handling, and treatment of warm blooded animals held for research, teaching, or other activities supported by the award of assistance.
- 16. Will comply with the Lead-Based Paint Poisoning Prevention Act (42 U.S.C. Sects. 4801 et seq.) which prohibits the use of lead based paint in construction or rehabilitation of residence structures.
- 17. Will cause to be performed the required financial and compliance audits in accordance with the Single Audit Act of 1984.
- 18. Will comply will all applicable requirements of all other Federal laws, executive orders, regulations and policies governing this program.

CERTIFICATIONS

1. CERTIFICATION REGARDING DEBARMENT AND SUSPENSION

By signing and submitting this proposal, the applicant, defined as the primary participant in accordance with 45 CFR Part 76, certifies to the best of its knowledge and belief that it and its principals:

- (a) are not presently debarred, suspended proposed for debarment, declared ineligible, or voluntarily excluded from covered transactions by any Federal Department or agency;
- (b) have not within a 3-year period preceding this proposal been convicted of or had a civil judgment rendered against them for commission or fraud or criminal judgment in connection with obtaining, attempting to obtain, or performing a public (Federal, State, or local) transaction or contract under a public transaction; violation of Federal or State antitrust statutes or commission of embezzlement, theft, forgery, bribery, falsification or destruction of records, making false statements, or receiving stolen property;
- (c) are not presently indicted or otherwise criminally or civilly charged by a governmental entity (Federal, State or local) with commission or any of the offenses enumerated in paragraph (b) of the certification; and
- (d) have not within a 3-year period preceding this application/proposal had one or more public transactions (Federal, State, or local) terminated for cause or default.

Should the applicant not be able to provide this certification, an explanation as to why should be placed after the assurances page in the application package.

The applicant agrees by submitting this proposal that it will include, without modification, the clause, titled "Certification Regarding Debarment, Suspension, In-eligibility, and Voluntary Exclusion -- Lower Tier Covered Transactions" in all lower tier covered transactions (i.e. transactions with sub-grantees and/or contractors) in all solicitations for lower tier covered transactions in accordance with 45 CFR Part 76.

2. CERTIFICATION REGARDING DRUG-FREE WORKPLACE REQUIREMENTS

The undersigned (authorized official signing for applicant organization) certifies that the applicant will, or will continue to, provide a drug-free workplace in accordance with 45 CFR Part 76 by:

(a) Publishing a statement notifying employees that the unlawful manufacture, distribution, dispensing, possession or use of a controlled substance is prohibited in the grantee's workplace and specifying the actions that will be taken against employees for violation of such prohibition;

- (b) Establishing an ongoing drug-free awareness program to inform employees about-
- (1) The dangers of drug abuse in the workplace;
- (2) The grantee's policy of maintaining a drug-free workplace,
- (3) Any available drug counseling, rehabilitation, and employee assistance programs; and
- (4) The penalties that may be imposed upon employees for drug abuse violations occurring in the workplace;
- (c) Making it a requirement that each employee to be engaged in the performance of the grant be given a copy of the statement required by paragraph (a) above;
- (d) Notifying the employee in the statement required by paragraph (a) above, that, as a condition of employment under the grant, the employee will-
- (1) Abide by the terms of the statement; and
- (2) Notify the employer in writing of his or her conviction for violation of a criminal drug statute occurring in the workplace no later than five calendar days after such conviction;
- (e) Notify the agency in writing within ten calendar days after receiving notice under paragraph (d)(2) from an employee or otherwise receiving actual notice of such conviction. Employers of convicted employees must provide notice, including position title, to every grant officer or other designee on whose grant activity the convicted employee was working, unless the Federal agency has designated a central point for the receipt of such notices. Notice shall include the identification number(s) of each affected grant;
- (f) Taking one of the following actions, within 30 calendar days of receiving notice under paragraph (d)(2), with respect to any employee who is so convicted-
- (1) Taking appropriate personnel action against such an employee, up to and including termination, consistent with the requirements of the Rehabilitation Act of 1973, as amended, or
- (2) Requiring such employee to participate satisfactorily in a drug abuse assistance or rehabilitation program approved for such purposes by a Federal, State, or local health, law enforcement, or other appropriate agency;
- (g) Making a good faith effort to continue to maintain a drug-free workplace through implementation of paragraphs (a), (b), (c), (d), (e), and (f).

For purposes of paragraph (e) regarding agency notification of criminal drug convictions, the DHHS has designated the following central point for receipt of such notices:

Division of Grants Policy and Oversight
Office of Management and Acquisition
Department of Health and Human Services
Room 517-D
200 Independence Avenue, S.W.

Washington, D.C. 20201

3. CERTIFICATION REGARDING LOBBYING

Title 31, United States Code, Section 1352, entitled "Limitation on use of appropriated funds to influence certain Federal contracting and financial transactions," generally prohibits recipients of Federal grants and cooperative agreements from using Federal (appropriated) funds for lobbying the Executive or Legislative Branches of the Federal Government in connection with a SPECIFIC grant or cooperative agreement. Section 1352 also requires that each person who requests or receives a Federal grant or cooperative agreement must disclose lobbying undertaken with non-Federal (non-appropriated) funds. The requirements apply to grants and cooperative agreements EXCEEDING \$100,000 in total costs (45 CFR Part 93).

The undersigned (authorized official signing for the applicant organization) certifies, to the best of his or her knowledge and belief that:

- (1) No Federal appropriated funds have been paid or will be paid, by or on behalf of the undersigned, to any person for influencing or attempting to influence an officer or employee of any agency, a Member of Congress, an officer or employee of Congress, or an employee of a Member of Congress in connection with the awarding of any Federal contract, the making of any Federal grant, the making of any Federal loan, the entering into of any cooperative agreement, and the extension, continuation, renewal, amendment, or modification of any Federal contract, grant, loan, or cooperative agreement.
- (2) If any funds other than Federally appropriated funds have been paid or will be paid to any person for influencing or attempting to influence an officer or employee of any agency, a Member of Congress an officer or employee of Congress, or an employee of a Member of Congress in connection with this Federal contract, grant, loan, or cooperative agreement, the undersigned shall complete and submit Standard Form-LLL, "Disclosure of Lobbying Activities," in accordance with its instructions. (If needed, Standard Form-LLL, "Disclosure of Lobbying Activities," its instructions, and continuation sheet are included at the end of this application form.)
- (3) The undersigned shall require that the language of this certification be included in the award documents for all subawards at all tiers (including subcontracts, subgrants, and contracts under grants, loans, and cooperative agreements) and that all subrecipients shall certify and disclose accordingly.

This certification is a material representation of fact upon which reliance was placed when this transaction was made or entered into. Submission of this certification is a prerequisite for making or entering into this transaction imposed by Section 1352, U.S. Code. Any person who fails to file the required certification shall be subject to a civil penalty of not less than \$10,000 and not more than \$100,000 for each such failure.

4. CERTIFICATION REGARDING PROGRAM FRAUD CIVIL REMEDIES ACT (PFCRA)

The undersigned (authorized official signing for the applicant organization) certifies that the statements herein are true, complete, and accurate to the best of his or her knowledge, and that he or she is aware that any false, fictitious, or fraudulent statements or claims may subject him or her to criminal, civil, or administrative penalties. The undersigned agrees that the applicant organization will comply with the Public Health Service terms and conditions of award if a grant is awarded as a result of this application.

5. CERTIFICATION REGARDING ENVIRONMENTAL TOBACCO SMOKE

Public Law 103-227, also know as the Pro-Children Act of 1994 (Act), requires that smoking not be permitted in any portion of any indoor facility owned or leased or contracted for by an entity and used routinely or regularly for the provision of health, day care, early childhood development services, education or library services to children under the age of 18 if the services are funded by Federal programs either directly or through State or local governments by Federal grant, contract, loan, or loan guarantee. The law also applies to children's services that are provided in indoor facilities that are constructed, operated, or maintained with such federal funds. The law doe not apply to children's services provided in private residences; portions of facilities used for inpatient drug or alcohol treatment; service providers whose sole source of applicable Federal funds is Medicare or Medicaid; or facilities where WIC coupons are redeemed. Failure to comply with the provisions of the law may result in the imposition of a monetary penalty of up to \$1,000 for each violation and/or the imposition of an administrative compliance order on the responsible entity.

By signing this certification, the undersigned certifies that the applicant organization will comply with the requirements of the Act and will not allow smoking within any portion of any indoor facility used for the provision of services for children as defined by the Act.

The applicant organization agrees that it will require that the language of this certification be included in any subawards which contain provisions for children's services and that all subrecipients shall certify accordingly.

The Public Health Service strongly encourages all grant recipients to provide a smoke free workplace and promote the non-use of tobacco products. This is consistent with the PHS mission to protect and advance the physical and mental health of American people.

5.3 Other Supporting Documents

Following is the NOTES section of the ERP. Please refer to these notes when reviewing the various forms described in Section 5.8

5.4 Core Health Status Indicator Forms

Following are the Core Health Status Indicator forms.

5.5 Core Health Status Indicator Detail Sheets

Following are the Core Health Status Indicator Detail Sheets.

5.6 Developmental Health Status Indicator Forms

Following are the Developmental Health Status Indicator Forms.

5.7 Developmental Health Status Indicator Detail Sheets

Following are the Developmental health Status Indicator Detail Sheets.

5.8 All Other Forms

Following are the required forms from the ERP: C Form 2: MCH Budget Details for FY 2000 SD 2.1 С Form 3: State MCH Funding Profile SD 3.1 C Form 4: Budget Details by Type of Individuals Served SD 4.1 С Form 5: State Title V Program Budget and Expenditures SD 5.1 С Form 6: Number and Percentage of Newborns and Others Screened SD 6.1 C Form 7: Number of Individuals Served SD 7.1 С Form 8: Deliveries and Infants Served by Title V SD 8.1 С Form 9: State MCH Toll-Free Telephone Line Reporting SD 9.1 С Form 10 State Profile SD 10.1 C Form 11: Tracking Performance Measures by Service Level (CORE) SD 11.CORE С Form 11 Attachments to CORE Performance Measures #2, #14 Attachments C Form 11: Tracking Performance Measures by Service Level (NEG) SD 11.NEG C Form 11: Attachment to NEG Performance Measures (NEG) #9 Attachment C Form 12: Tracking Health Outcome Measures SD 12.CORE C Form 13: Service System Constructs for CSHCN SD 13.1 C Form 14: List of MCH Priority Needs SD 14.1 С Form 15: Technical Assistance Request and Tracking Form SD 15.1

5.9 National "Core" Performance Measure Detail Sheets

Following are the National Core Performance Measure Detail Sheets.

5.10 State "Negotiated" Performance Measure Detail Sheets

Following are the State Negotiated Performance Measure Detail Sheets.

5.11 Outcome Measure Detail Sheets

Following are the Outcome Measure Detail Sheets.

APPENDIX A

STANDING ADVISORY COUNCILS/COMMITTEES/TASK FORCES

OVERALL MCH:

- State Council on Maternal, Infant, and Child Health (MICH)
- South Carolina Medical Association and its Maternal, Infant and Child Committee, and Prematurity Prevention Subcommittee
- Alliance for S.C.'s Children
- Commissioner's Pediatric Advisory Committee
- Healthy Start Management and Advisory Groups for two of the three Healthy Start projects in SC, and Healthy Start Collaborative with all three projects
- Infant Mortality workgroup
- DHEC/USC MCH Integration group
- Statewide Lead Poisoning Prevention Advisory Committee
- Commissioner's Obstetric Task Force
- South Carolina Medical Association (SCMA) Maternal, Infant, and Child Health Committee
- Minority Health Task Force
- MICH Service Plan Committee
- Family Practice Advisory Committee

DIVISION OF WOMEN AND CHILDREN'S SERVICES

- Dept. of Health and Human Services/DHEC Joint Committee
- Fetal Alcohol Syndrome Network
- South Carolina Dietetic Association
- Childhood Injury Prevention Action Council
- Pediatric AIDS Ad-Hoc Committee
- Metabolic/Newborn Screening Committee
- Family Support Service Training Team
- Joint DHHS/DHEC/SCMA Partnership Promotion Committee
- Medicaid Mega Contract Interagency workgroup

DIVISION OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS SECTION OF CHILDREN'S REHABILITATIVE SERVICES

- CRS Medical Advisory Board
- CRS/BabyNet Parent-Provider Advisory Committee
- Commissioner's Pediatric Task Force on Children's Issues
- Program Advisory Committee (UAP)
- Genetics Task Force
- Continuum of Care for Emotionally Disturbed Children Advisory Council
- South Carolina Developmental Disabilities Council
- Sickle Cell Foundation Group
- Department of Mental Health State Planning Council's Children's Committee
- Statewide Needs Assessment of CSHCN Interagency Workgroup (inactive)
- Pediatric Emergency Medical Services Advisory Committee
- Assistive Technology Advisory Committee
- Universal Newborn Hearing Screening Advisory Council
- MICH CSHCN Sub-Committee

BABYNET SECTION

• Interagency Coordinating Council for PL 105-17 of IDEA (BabyNet) - including 12 committees and sub committees

DIVISION OF WIC

DHEC Nutrition Materials Review Committee (Chairperson)

- SC Breastfeeding Coalition Steering Committee
- WIC Food Package Committee (state-wide)
- Southeastern Regional Nutrition Workgroup (WIC)
- Minority Health Issues Task Force
- SCPHA Nutrition Section (Chair-Elect)
- Lexington Five Health Education Advisory Committee
- Southern Health Association
- South Carolina Nutrition Council
- Minority Health Issues Conference Steering Committee and Conference Committee
- DHEC Cultural Competence Workgroup
- Midlands Breastfeeding Coalition
- SC Breastfeeding Coalition
- National WIC Nutrition Representative for Southeastern Region
- USDA Regional integrity Workgroup
- USDA Regional Employee/Participant Abuse
- SC Public Health Association
- USDA Technology Committee

DIVISION OF PERINATAL SYSTEMS

- My Baby Keepsake Governor's Advisory Committee
- S.C. March of Dimes
- South Carolina State Perinatal Board and four Regional Perinatal Boards
- South Carolina Perinatal Association
- SC Child Protection Advisory Committee
- SC Child Fatality Advisory Committee
- Southeast Coalition on Prevention and Investigation of Child Deaths
- SIDS Alliance of the Carolinas
- SC March of Dimes Chapter Program Services Committee

BUREAU OF COMMUNITY HEALTH

- Turning Point Faith and Health Network
- Palmetto Faith and health Consortium
- Health Ministry Association Carolinas Chapter
- Interfaith Community Services of South Carolina
- SC Society for Congregational Nursing
- SC Allied Health Association Executive and Legislative Committee Representative
- Healthy Communities Collaborative
- S.C. Advisory Council on the Education of Individuals with Disabilities
- Hold Out The Lifeline A Mission to Families
- Hold Out The Lifeline State Steering Committee member
- Hold Out The Lifeline Conference Planning Committee
- Carolinas Healthy Ministries Association
- Teen Pregnancy Prevention Committee
- Healthy School Environmental Task Force, SDE
- School Nurse Program Advisory Committee, DHEC, SDE
- SC School of Promise Task Force, SCASA
- SC Healthy Schools Network, American Cancer Society
- Annual School Nurse Conference Planning Committee, DHEC, SDE
- Governor's Immunization Outreach Committee
- Hope for Kids Committee

APPENDIX B MCH AND CRS FUND ALLOCATION

MCH ALLOCATION

MCH Block Grant funds are allocated in accordance with the 30-30 minimum funding requirements. The MCH allocation system to the districts is entering into a new four-year period. A workgroup in early SFY 2000, comprised of central office and district staff, reviewed the allocation system and methodology that was in place, and developed the following approved recommendations:

- 1. An application be submitted annually by each district that will include:
 - a. A description of the health care system for the MCH population in that district;
 - b. An MCH Annual Plan describing how performance areas will be addressed;
 - A budget describing how the Districts Title V and State allocations for Maternity and Child
 Health will be used in accordance with Budget Form 5.
- 2. Each District will submit a annual report reflecting how well current year objectives are being met.
- 3. The Title V and State Funding will be allocated to Districts via a formula which guarantees a percentage of the FY 1996 base, with the balance allocated on combined need and health indices. The allocation will become more need and health indices based over time. The base percentage will move to 50% over a four year period in accordance with the following below. Need will be defined as the percentage of reproductive age women and children below the federal poverty level. The health indices will consist of IMR, teen pregnancy rate, early entry into prenatal care, and ambulatory care sensitive hospitalizations. The need figures will be updated to reflect the 2000 census when data is available and the health indices numbers will be updated yearly. The allocation formula will change over the four years as follows:

FY 2001	65.0% BASE	35.0% NEED/HEALTH INDEX
FY 2002	60.0% BASE	40.0% NEED/HEALTH INDEX
FY 2003	55.0% BASE	45.0% NEED/HEALTH INDEX
FY 2004	50.0% BASE	50.0% NEED/HEALTH INDEX

The formula will be reviewed during SFY 2004, and any changes implemented at the beginning of SFY 2005.

- 4. If there is a reduction in funds:
 - The base allocation will be covered first, with any remaining funds distributed on the Need/Health Index;
 - b) If the funding is not sufficient to cover the base, a new base would be created by applying the percentage of the current base for each District to the amount of funds available to allocate (e.g.,

if District A has 2% of the current total funds allocated for base, District A would receive 2% of the reduced amount of funds to be allocated. The following year, the formula would resume. Any additional funds in the next year would be used to restore the original base and the balance distributed on need and health index.

A copy of the District MCH Application Guidance is provided in **Appendix C**. This document provides the clear linkage between planning and allocation of funds.

This revised allocation process provides Districts with the flexibility needed to respond to changes in service delivery to Medicaid clients and to encourage Districts to approach the needs of the population in more creative ways, not so strictly tied to projections of the numbers of each service provided. By freeing funds from the constraints of specific services, of which many are Medicaid reimbursable, Districts can be more responsive to the MCH population in their communities through a more thorough assessment of local needs, while preparing for change.

Freeing funding from such a service driven philosophy also enables the Title V program to maximize the opportunities to continue building partnerships with other public agencies, private providers and organizations to strive for a fully integrated system of care for mothers and children. This in only one of the documented essential public health functions related to systems development identified as part of MCH's role in a redefined health care system.

We will continue to monitor the direct provision of MCH services through the existing reporting system in each program and through the agency's cost accounting system. The agency continues to work on thoroughly reviewing the actual cost of services provided through the costing system. Having more accurate cost data will enable us to better facilitate getting actual cost reimbursed through Medicaid contracts.

CRS Allocation

Maximize funds to the Districts

The CRS Director will review all resources available to the Program and make a recommendation to the Maternal and Child Health Bureau Director as to the funding available to be allocated to the Districts. Once approved, this will be submitted to the Deputy Commissioner of Health Services for approval. In no case will the amount of funding allocated to the Districts in the prior year be decreased unless there is substantial amount of reduction in the Federal or State allocation to the CRS Program. Even under these circumstances, every attempt will be made

to maintain the District's funding level.

Ensure Equitable Distribution of Funds

To ensure equitable distribution, funds are continuing to be allocated beginning in FY 99 on a percentage of the FY 98 base plus a weighted score for each of the four CRS indicators. These include: 1) Active Caseload, 2) New Admissions, 3) Clinic Visits, and 4) Out of District Patients Served.

This system is being phased in as follows:

FY=	Base	Indicators
1999=	95%	5%
2000=	90%	10%
2001=	85%	15%
2002=	80%	20%

- 1. Stop at 80% base and 20% indicators;
- 2. FY 98 allocations will be used as the base year;
- 3. The most recent four quarters of data will be used to provide the data for the indicators;
- 4. To ensure clinical funding is available, clinician funding will be given in addition to each District's formula allocation.

New Clinics

If a District wants to establish new clinics, a proposal is sent to the Program Director of CRS explaining the need for the clinic and an estimate of the funding needed to start the clinic. The CRS Director will then examine the operational plan submitted by the District and meet with the District to determine the need for the clinic. If it is agreed that the new clinic is beneficial to the special needs children in that community, the CRS Director will ask for funding through the appropriate channels of communication in the Agency. If the new clinic is funded, these funds would be placed in the District's CRS budget. AFTER 12 MONTHS THESE FUNDS WOULD BE ROLLED INTO THE CRS ALLOCATION SYSTEM.

Note: This system requires CRS Central Office to conduct record reviews on a periodic basis to ensure that caseload data and clinic visit data is as accurate as possible for the allocation system.

Also, patients not receiving a service in two years on the data system are counted in the active caseload data.

Operational Plan

In order for the CRS Program to monitor and manage Program effectiveness and efficiency, each District submits an operational plan for the CRS services to be provided with the allocation they receive on the formula method. This could include, but not be limited to such things as caseload, number of new admissions, numbers and types of clinics to be held, numbers and types of FTE's needed to run the Program and a brief description of the service system for special needs in the local areas. This plan is reviewed by the CRS Central Office staff who work with the Districts on effectiveness and efficiency of the CRS services. The operational plan should not be over 2 pages and is developed by the CRS Coordinators in each District. This plan should be used to fit into the overall operational plan for the District and the MCH plan. The CRS Central Office and District staff are working to develop staffing standards that are being used to establish core staff needed to manage the CRS Program to assist in monitoring efficiency.

Transition to Systems of Care

If a District is in a situation in a community where they want to use some of their existing resources to move into a partnership and decrease direct services provided, they may write a proposal to the CRS Director. The proposal should describe the role of CRS in the community and how the change will impact on direct services currently provided. It should also identify how much funding from the current allocation system would be placed into the new direction. If the CRS Program and the District agree that this is a change that would better serve special needs children in that community, these funds will be removed from the formula allocation process and will be given to that District in addition to funds earned through the formula. **The Districts FY 98 base would be reduced by the amount of funds directed into systems.**

Conclusion

The allocation of block grant funds for Children's Rehabilitative Services (CRS) is based on the individual caseload and staffing in each CRS clinic. Embracing the philosophy of family-centered, community-based, coordinated care, CRS funds 13 Districts throughout the state. Funds are allocated to one additional District to provide home based follow-up care in the patient's county of residence. In addition, there are specialty clinics in five areas of the state where regional medical centers are located. Patients referred to these clinics for appropriate medical care receive case management services and follow-up care in their home regions/district.

APPENDIX C

GUIDANCE FOR DISTRICTS TO COMPLETE PART 2 OF THE MCH PLAN FOR STATE FISCAL YEAR 2001

April 25, 2000

Maternal and Child Health Bureau

Health Services, DHEC

TABLE OF CONTENTS

- A. Background
- B. Part 2 of the MCH planning process
- C. Budget
- D. Time line and Plan Review Process

A. BACKGROUND

Every district submitted a description of the systems of care for the MCH populations (called Part I) of their SFY 2001 MCH plan in March, 2000. That information was shared with and incorporated into the work of the 5-year MCH needs assessment population workgroups. At the MCH Team meeting in April, the workgroups gave their final reports on priorities and recommendations for the state for their respective populations. That work in turn generated the new state performance measures that when combined with the 18 federal measures and the six federal outcome measures, provide an indication of how we are doing as a state on many of the most important MCH issues that confront us. The measures do not reflect all of the many and diverse activities and programs that MCH in South Carolina conducts in the state, but they do provide a good grouping of indicators to monitor progress.

The final needs assessment document will be shared with program staff in central office and in the districts to make sure that the detail and substance of the work is conveyed. Many of the recommendations do not lend themselves to performance measurement, but are very important and merit reflection for possible future actions.

B. WHAT DISTRICTS HAVE TO DO FOR PART 2 OF THE 2001 MCH PLAN

The reporting format for this year are similar in form to last year. Reporting requirements have been kept to a minimum. Wherever possible, data and reports that are already generated for other activities will be used for the MCH Block Grant. For example, immunization data and reports will be used for federal measure number 5 (immunization levels in two year children). Districts are being asked to report on only 18 of the 27 measures via the MCH planning process.

Please use the systems overview and analysis work generated in Part I of the District plan when describing past and present efforts on the various performance measures.

Refer to the enclosed DISTRICT SUMMARY GUIDE TO COMPLETE THE 2001 MCH 5 YEAR PLAN (electronically called "pmguit~1"). It contains two columns:

- The first column, **PERFORMANCE MEASURE**, is the actual performance measure (18 federal and 9 state). The bold face type indicates the type of measure (capacity, risk-factor or process) as well as the type of service: direct health care service, enabling service, population-based service or infrastructure building (see pyramid diagram following for a graphic display of the levels of service).
- 2) The second column, **INSTRUCTIONS FOR THE SFY 2001 DISTRICT MCH PLAN** describes what information and/or plan the District needs to submit for that measure. Boxes shaded in gray mean that no reporting is required from the District for that measure since the measure is being reported on elsewhere.

For the 18 measures that do require District input, an explanation is given of what is needed for each measure. Technical Assistance contacts are included, and data issues are also described.

Templates for each measure are attached electronically ("distem01") to facilitate and standardize reporting. If a hard copy of the guidance or templates is needed, "save as" the Word Perfect document onto the hard drive, and print out in Word Perfect.

- 3) Other report required by the Title V program: Complete the two questions on the attached template. The state will then compile to answer this federal requirement.
- 4) Three state performance measures from last year that are not being carried forward this year need an updated report describing accomplishments in FY 2000. These reports should be summary statements only. The template for these is included in the template document as well.

C. BUDGET

Districts are requested to complete the budget sheets as in years past. Janet Sheridan in Health Services Administration will be sending out to the DAs and DHDs by mid-May the tentative Title V District allocations for FY 2001 with the needed forms to complete the financial information. The completed budget information should be sent back in together with the rest of the District MCH plan submission.

D. TIME LINE AND PLAN REVIEW PROCESS

4/25/20	Plan guidance distributed,
4/26/20-6/22/20	Districts work on plans, TA provided by central office Epi and Program staff.
5/2/20	Deadline for Districts to request site visit TA. E-mail Joe Kyle with request.
5/15/20-6/6/20	TA site visits to Districts that request assistance.
6/23/20	Plans due in Central Office.
6/26/20-7/14/20	Plans reviewed by Program staff
7/18/20	Plan Review Day. Central office and District staff invited.
8/4/20	Review feedback sent out to Districts
8/7/20-8/31/20	Debriefing site visits to those Districts that request the visit and that did not receive a
	May visit.

CORE PUBLIC HEALTH SERVICES **DELIVERED BY MCH AGENCIES**



Examples: Basic Health Services, and Health Services for CSHCN

ENABLING SERVICES:

Examples:

Transportation, Translation, Outreach, Respite Care, Health Education, Family Support Services, Purchase of Health Insurance, Case Management, Coordination with Medicaid, WIC, and Education

POPULATION-BASED SERVICES:

Examples: Newborn Screening, Lead Screening, Immunization, Sudden Infant Death Syndrome Counseling, Oral Health, Injury Prevention, Nutrition and Outreach/Public Education

INFRASTRUCTURE BUILDING SERVICES:

Examples:

Needs Assessment, Evaluation, Planning, Policy Development, Coordination, Quality Assurance, Standards Development, Monitoring, Training. Applied Research, Systems of Care, and Information Systems

APPENDIX D

DISTRICT SUMMARY PERFORMANCE MEASURE REPORTING GUIDANCE

FY 2001

DISTRICT SUMMARY GUIDE TO COMPLETE THE 2001 MCH 5 YEAR PLAN

FEDERAL PERFORMANCE MEASURES

PERFORMANCE MEASURE	INSTRUCTIONS FOR THE SFY 2001 DISTRICT MCH PLAN
1. The percent of State SSI beneficiaries less than 16 years old receiving rehabilitative services from the State CSHCN program. Capacity/DHCS	1. No plan is required for this measure. CRS staff are obtaining this data and will share if requested.
2. The degree to which the State CSHCN program provides or pays for specialty and subspecialty services, including care coordination, not otherwise accessible or affordable to its clients. Capacity/DHCS	2. This information is already provided in the CRS operational plan. No additional information is required for the MCH plan.
3. The percent of CSHCN in the State who have a medical home. Capacity/ENABLING	3. Until the national survey of CSHCN is completed, South Carolina will continue to sample 10 percent of CRS case files to determine the percentage of CRS children who have a primary care provider. This data will be the basis for responding to this performance measure. District partnering activities are described in the operational plan as well as in the Mega Contract reports, which adequately describe these efforts. No additional information is required for the MCH plan.
4. Percent of newborns in the State with at least one screening for each of PKU, hypothyroidism, galactosemia, hemoglobinopathies (combined) screened by State sponsored programs for genetic disorders. Risk-Factor/POP BASED	4. No plan is required for this measure. There is a state-wide screening program in place via the hospitals, and all Districts follow-up with any positives that are detected. Data reports are available and are monitored by the program at the state level.
5. Percent of children through age 2 who have completed immunizations for measles, mumps, rubella, polio, diphtheria, tetanus, pertussis, haemophilus influenza, hepatitis B. Risk Factor/POP BASED	5. No separate plan is required for this measure. District activities and plans are described through the Childhood Immunization Grant. Much data also exists on immunization status within and outside of the DHEC system, and is available from the Division of Immunization.

PERFORMANCE MEASURE	INSTRUCTIONS FOR THE SFY 2001 DISTRICT MCH PLAN
6. The rate of births (per 1,000) for teenagers aged 15 through 17. Risk Factor/POP BASED	6. MCH Epidemiology (Dr. Donna Rickert (803)-898-0875) is providing data, assessment and analysis support. Based on this assessment, Districts will need to: describe their accomplishments this year, including whether their target was reached; the target for next year, and a description of next year's plans to address this issue, through Title X, the Family Planning Waiver, and other MCH efforts. Sarah Cooper (803-898-0776) and Kahlil Demonbreun (803)-898-0369 of the Division of Women and Children's Services are available for program expertise. Submit response on the attached template.
7. Percent of third grade children who have received protective sealants on at least one permanent molar tooth. Risk Factor/POP BASED	7. Describe activities being done or planned in public health dentistry (submit plan on the attached template). With the increased Medicaid reimbursement for dental services, any partnership efforts with dental providers should be highlighted. Please indicate if any formal partnerships exist with providers in any of the counties in the District. Specific data for this measurement are not available presently. Contact Dr. John Simkovich at (843)-740-0800 for assistance in developing public health dentistry interventions.
8. The rate of deaths to children aged 1-14 caused by motor vehicle crashes per 100,000 children. Risk Factor/POP BASED	8. MCH Epidemiology (Dr. Donna Rickert (803)-898-0875) is providing data, assessment and analysis support. Based on this assessment, Districts will need to: describe their accomplishments this year, including whether their target was reached; the target for next year; and a description of next year's plans to prevent childhood fatalities from motor vehicle accidents within the District. Efforts that are already being reported to the Division of Injury Prevention can be referenced for reporting ease. Leroy Frazier (803)-898-0314 of the Division of Injury Prevention is available for program expertise. Submit response on the attached template.
9. Percentage of mothers who breastfeed their infants at hospital discharge. Risk Factor/POP BASED	9. Districts already submit an annual breastfeeding plan, and do not need to add anything else to the MCH plan for this measure. Data for the state will be captured from the Newborn Screening reporting system. This data is available through the Division of WIC.
10. Percentage of newborns who have been screened for hearing impairment before hospital discharge. Risk Factor/POP BASED	10. Districts do not need to add anything to the MCH plan for this measure. Program staff continue to monitor activities and data collection for the state.

PERFORMANCE MEASURE	INSTRUCTIONS FOR THE SFY 2001 DISTRICT MCH PLAN
11. Percent of CSHCN in the State program with a source of insurance for primary and specialty care. Capacity/IF BLDG	11. Districts do not need to add anything to the MCH plan for this measure. The CRS data system captures this for state-wide measurement.
12. Percent of children without health insurance Capacity/INF BLDG	12. Due to the Mega-Contract reporting system, no additional information is required that describes ongoing efforts. However, if Districts have any plans for enhancing or changing their outreach strategies for next year, describe them on the attached template. Angie Olawsky (803)-898-0617 and Sarah Cooper (803)-898-0776 of the Division of Women and Children's Services are available for program expertise.
13. The rate (per 100,000) of suicide deaths among youths aged 15-19. Risk Factor/INF BLDG	13. MCH Epidemiology (Dr. Donna Rickert (803)-898-0875) is providing data, assessment and analysis support. Based on this assessment, Districts will need to: describe their accomplishments this year, including whether their target was reached; the target for next year; and a description of next year's plans to reduce suicides in youth. Sandra Jeter (803)-898-0814 of the Office of Social Work is available for program expertise. Submit response on the attached template.
14. Percent of very low birth weight live births. Risk Factor/INF BLDG	14. MCH Epidemiology (Dr. Donna Rickert (803)-898-0875) is providing data, assessment and analysis support. Based on this assessment, Districts will need to: describe their accomplishments this year, including whether their target was reached; the target for next year; and a description of next year's plans to address low birth weight. Sarah Cooper (803-898-0776) and Kahlil Demonbreun (803)-898-0369 of the Division of Women and Children's Services, and Luanne Miles (803)-898-0727 of the Perinatal Program are available for program expertise. Submit response on the attached template.
15. Percent of potentially Medicaid eligible children who have received a service paid by the Medicaid program. Process/INF BLDG	15. Due to the Mega-Contract reporting system, Districts do not need to describe ongoing outreach and partnership activities that have an impact on the potentially eligibleto eligibleto receiving a primary care service continuum However, if Districts have any plans for enhancing or changing their systems work for next year, please describe them on the attached template. Angie Olawsky at (803)-898-0617 or Sarah Cooper at (803)-898-0776, of the Division of Women and Children's Services are available for program expertise. Submit response on the attached template.

PERFORMANCE MEASURE	INSTRUCTIONS FOR THE SFY 2001 DISTRICT MCH PLAN
16. The degree to which the State assures family participation in program and policy activities in the State CSHCN program. Process/INF BLDG	16. Describe parent involvement (ongoing and for next year) in the District CRS program including parent support and parent advisors this year, and plans for next year. Sarah O'Brien (803)-898-0348 is available for program expertise. Submit response on the attached template.
17. Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates. Risk Factor/IF BLDG	17. MCH Epidemiology (Dr. Donna Rickert (803)-898-0875) is providing data, assessment and analysis support. Based on this assessment, Districts will need to: describe their accomplishments this year, including whether their target was reached; the target for next year; and a description of next year's plans. Include a description of the coordination with the RSD in the Perinatal Region and please address referral systems, communication, and systems issues. Luanne Miles (803)-898-0727, Perinatal Program, is available for program expertise. Submit response on the attached template.
18. Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester. Risk Factor/IF BLDG	18. MCH Epidemiology (Dr. Donna Rickert (803)-898-0875) is providing data, assessment and analysis support. Based on this assessment, Districts will need to: describe their accomplishments this year, including whether their target was reached; the target for next year, and a description of next year's plans to address first trimester entry. Please include a specific reference to WIC first trimester entry. Sarah Cooper (803-898-0776) and Kahlil Demonbreun (803)-898-0369 of the Division of Women and Children's Services, Luanne Miles (803)-898-0727 of the Perinatal Program, and Burnese Walker-Dix (803) 898-0744 of the WIC Division, are available for program expertise. Submit response on the attached template.

STATE PERFORMANCE MEASURES

PERFORMANCE MEASURE	INSTRUCTIONS FOR THE SFY 2001 DISTRICT MCH PLAN
1.Percent of Medicaid newborns in the state receiving a home visit. Risk Factor/DHCS	1. This measure has been slightly changed for this year and now includes all Medicaid newborns, not just those visited by DHEC. Describe ongoing efforts this year and planned activities in SFY 2001 to increase Medicaid new born home visits, and strategies the District will use to assure that Medicaid newborns receive a visit, whether by DHEC or not. Angie Olawsky (803)-898-0617 and Sarah Cooper (803)-898-0776, Division of Women and Children's Services, are available for program expertise. Submit response on the attached template.
2. Percent of women giving birth with an unintended pregnancy. Risk Factor/POP BASED	2. Describe ongoing efforts this year and planned activities for SFY 2001 to reduce unintended pregnancies in the District. Data is available through PRAMS at the state level. Dr. Donna Rickert (803)-898-0875, and Kristen Helms ((803)-898-3624, PRAMS Coordinator, are available for assessment and analysis, and Sarah Cooper (803-898-0776) and Kahlil Demonbreun (803)-898-0369 of the Division of Women and Children's Services are available for program expertise. Submit response on the attached template.
3. Percent of counties that have a formal partnership with their local school district(s) which includes assuring access to a medical home and age appropriate health education services for school children. Capacity/POP BASED	3. The wording of this measure has changed substantially from last year, which measured the ratio of school nurses to the student population, but the intent of the measure is similar: increase school children's access to primary care and health education services. The measure now more accurately reflects that intent. Describe ongoing efforts this year and planned activities in SFY 2001 to coordinate primary care and health education activities with schools (including school nurses). Mention by name the counties that have a formal (written agreement) partnership in place. Libby Brown (803)-898-0620, Division of Adolescent and School Health and Angie Olawsky (803)-898-0617 Division of Women and Children's Health, are available for program expertise. Submit response on the attached template.
4. Percent of Districts with an injury prevention program in place. Capacity/POP BASED	4. This measure has been modified for this year to incorporate intentional injuries and other MCH populations. There are two questions that need a yes or no response. In addition, describe efforts this year that address unintentional injuries, and for 2001, describe plans to address unintentional and intentional injuries, and which MCH populations will be reached. Leroy Frazier (803)-898-0314 of the Division of Injury Prevention is available for program expertise. Submit response on the attached template.

PERFORMANCE MEASURE	INSTRUCTIONS FOR THE SFY 2001 DISTRICT MCH PLAN
5. The degree to which the State assures a transition is developed for those children aging out of the State CSHCN program. Capacity/INF	5. This data will be compiled at the state level. No other reporting is required from the Districts for the MCH plan.
6. Percent of high school students who smoke. Risk Factor/POP BASED	6. Local data is not available. For the state, 36 percent of high school students in 1999 reported having smoked in the last thirty days. Describe ongoing and planned efforts to reduce teen smoking for 2001. Include efforts reported to other non MCH programs. Susan Cate (803)-898-0754 in the Division of Chronic Disease is available for program expertise. Submit response on the attached template.
7. Percent of counties with obstetrical partnerships that include ensuring access to risk appropriate and quality care. Capacity/INF	7. Describe ongoing and planned formal partnership efforts for FY 2001 with the obstetrical community in the District/counties. Mention by name the counties that have a formal partnership in place. Include a description of the mechanisms to ensure risk appropriate and quality care, and the specific components of the partnership. Sarah Cooper (803-898-0776) and Angie Olawsky (803)-898-0617 Division of Women and Children's Health, are available for program expertise. Submit response on the attached template
8. Percent of children four and above who are obese. Risk Factor/POP BASED	8. Describe ongoing and planned activities through FSS, school health and nutrition promotion, WIC and other special projects, that address childhood obesity. Include physical activity interventions. Burnese Walker-Dix (803) 898-0744 is available for program expertise. Submit response on the attached template.
9. Percent of counties with a pre and interconceptional health promotion program in place. Capacity/POP BASED	9. This measure requires completing a check-off table and including a brief narrative description that describes plans for next year to increase individual and community access to pre and interconceptional services and health promotion messages. Luanne Miles (803)-898-0727 and Elin Holgren (803)-898-0771 of the Division of Community Development, and Sarah Cooper (803-898-0776) and Kahlil Demonbreun (803)-898-0369 of the Division of Women and Children's Services are available for program expertise.

OTHER REPORT REQUIRED BY THE FEDERAL TITLE V PROGRAM:

The degree to which the State has service systems for children with or at risk of chronic and disabling conditions, as required by Public Law 101-239*

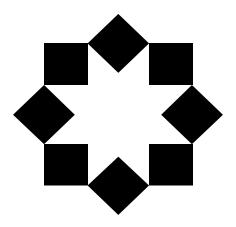
Complete the two questions on the attached template. The state will then compile to answer this federal requirement. Contact Kathy Semon (803)-898-0608 for program expertise.

PERFORMANCE MEASURE FROM LAST YEAR THAT NEEDS A PROGRESS REPORT ONLY FOR SFY 2000

1. Race specific mortality rate from SIDS. Risk Factor/POP BASED	1. This measure and all others in this category were dropped for FY 2001. For the MCH plan what is needed on each of these measures is a description of progress made this last year. Please contact Dr. Donna Rickert (803)-898-0875 for assessment expertise, and Elin Holgren (803)-898-0771 and Luanne Miles (803)-898-0727, Division of Community Development, for program expertise. Submit response on the attached template.
2. Percentage of counties that have a process which assesses health status, identifies resources and gaps in health services, plans based on the assessment, and implements activities to reach specific goals. Capacity/IF BLDG	2. Complete the attached checklist that covers this year with a ½ page narrative that summarizes these efforts, for each county that has begun an assessment process. It is understood that if no demonstrable activities have taken place, then no submission for that county is required. Please contact Elin Holgren (803)-898-0771 Division of Community Development. Submit response on the attached template.
3. Percentage of infants born to Black women who entered prenatal care in the first trimester. Risk Factor/INF BLDG	3. Contact Dr. Donna Rickert (803)-898-0875 for assessment expertise, and Elin Holgren (803)-898-0771 and Luanne Miles (803)-898-0727, Division of Community Development and Burnese Walker-Dix (WIC) (803)-898-0744 for program expertise. Submit response on the attached template. Include efforts this year to improve first trimester entry, particularly among minority women. Submit response on the attached template.

APPENDIX E

Shaping a Responsive System of Care



A Follow-Up Study Exploring the Needs
Of
Children with Special Health Care Needs

Report developed by
The Institute for Families in Society
University of South Carolina
Columbia, SC 29208
803-777-9124

Acknowledgments

The Institute for Families in Society at the University of South Carolina prepared this report under contract with the Title V Program, Children's Rehabilitative Services, South Carolina Department of Health and Environmental Control. This report could not have been possible without the caregivers and key informants who unselfishly gave of their time that we might all benefit from their experiences. Special recognition goes to the members of the Needs Assessment Advisory Committee and the staff of Family Connections, Inc. for their guidance and their work in engaging families to participate in this undertaking.

The contents of this report *may not* be reproduced without the permission of the Institute for Families in Society and Children's Rehabilitative Services, SC Department of Health and Environmental Control. Citation of the source is appreciated.

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Chapter One

Introduction and Summary

pproximately 15% to 18% of children in the United States have a special health care need or chronic health condition (Newacheck, et al., 1992). They and their families may have a large variety of health-related needs over and above those of their healthy peers. Families and their primary care physicians are centrally responsible for identifying, obtaining, coordinating, and monitoring a wide range of services for these children. The number and type of needs and services they identify depend in part on the particular condition(s) the child has, its manifestations and severity, the child's age, the parents' socioeconomic circumstances, and the particular medical care arrangements available to the family.

South Carolinians with children with special health care needs have reported problems in accessing health care services, coordination between primary and specialty care providers and multiple agencies (SC Statewide Needs Assessment , 1999). Thus, developing community systems of services for children with special health care needs represents a significant challenge for pediatricians, families, public and private agencies, and health care organizations providing services to this population. At the state level, Maternal and Child Health (MCH) and Children with Special Health Care Needs (CSHCN) programs are vested with the responsibility for planning and developing systems of care for all children with special health care needs. Historically, these programs have been supported through Title V of the Social Security Act, with state matching funds, to provide health services to selected groups of children with special needs, typically those with complex physical conditions (McPherson et al., 1998).

Purpose

Every five years, to gain an understanding of service system changes, the state Title V program conducts a needs assessment to identify the service needs of special needs

children, their families, and the gaps in service areas [Section 505 (a)(1) of the Social Security Act]. This report documents the efforts of a follow-up study to the 1994 Statewide Needs Assessment of Children with Special Health Care Needs. It builds on the foci of the 1994 Needs assessment:

- to estimate the unmet needs for all services;
- to assess the content and timing of services; and
- to identify barriers to services delivery.

As in the 1994 Needs Assessment effort, the ultimate purpose of this study is to gather information to inform policy decisions that foster service delivery systems for children with special health care needs that are coordinated, comprehensive, community-based, family-centered, and culturally competent.

This report represents all the areas explored in conducting this follow-up study. The research approach consisted of four discrete components:

- Advisory Committee. A group of 16 individuals representing community-based parent organizations of children with special health care needs and staff from the SC Department of Health and Environmental Control Title V and Maternal and Child Health units provided input into the overall design of the approach, reviewed the findings, and contributed to framing the final recommendations of the study.
- <u>Key Informant Interviews.</u> A total of 15 key informant interviews were conducted with stakeholders, policy makers and agency administrators familiar with the health care system and knowledgeable about children with special health care needs and their families.
- Focus Groups. Eight focus groups were conducted statewide with caregivers of children with special health care needs with two distinct populations, i.e., caregivers who participated in the 1994 Needs Assessment and caregivers with similar characteristics who did not participate in the 1994 study. Additionally, two focus groups were conducted with young adults with disabilities and one focus group with the Title V Medical Advisory Group.

 <u>Follow-Up Surveys</u>, A total of 49 surveys were mailed to caregivers of children with complex medical conditions under- represented among focus group participants.

This reports summarizes the findings from all of these distinct components. It illustrates the knowledge and experiences of key stakeholders, caregivers and young adults with special health care needs. It examines the findings and implications of this significant study.

Study Organization

The Institute for Families in Society at the University of South Carolina, in collaboration with Family Connections, Inc., facilitated the work of this study. The staff of the Institute for Families in Society took principal responsibility for the administrative and technical coordination of the study, development of the study tools, data collection, data processing, and data analysis. Family Connections, Inc. took responsibility for helping to facilitate the participation of consumers in this study. This collaborative approach took advantage of the resources and knowledge base of both organizations.

The study sought to involve a wide constituency of individuals with direct information and linkages to children with special health care needs. A multi-method approach was employed to minimize the inherent difficulties in using a single approach, i.e., qualitative versus quantitative. Thus, the quantitative surveys were enriched by the qualitative focus groups and key informant methodologies.

Summary of Key Findings

This summary provides an overview of the results of this study. The key issues identified were similar across geographic areas, segments of the population and service needs. Overall, the findings indicate a need for enhanced health care coverage, increased access to providers (i.e., medical and related-services, transportation and therapies), facilitation of educational, recreational, social, and employment opportunities for children and young adults with disabilities, and increased collaboration and training of providers to address the complexity of care needed by individuals with disabilities across the life span.

Findings For Children with Special Health Care Needs

The study documented the following needs:

Financial Access to Health Care Coverage

- Increased insurance coverage across all age groups.
- Need for increased number of Specialty Care Providers.
- < Equal coverage for mental health and physical disabilities.
- Increased availability of home health services (Skilled Nursing and Respite Care).
- < Expansion of coverage for therapies outside of educational settings.

System of Care

- Training of medical providers on assistive technology to address assessment and prescription needs.
- Greater need for skilled child care and respite care services.
- Increased coordination of care across agencies and providers to ensure continuity of care.
- Increase coordination across funding streams to facilitate a comprehensive system of care.
- < Greater need for school-based health care services and coordination with health care providers to ensure continuity of care and maximize children's potential to learn.
- Reduction of "red tape" by creating a central point of access to public health services.
- Eliminate geographical access to health services disparities.
- Increase vocational opportunities for children with special heath care needs.

Access to Social Support and Recreational Services

Increase access to family support and year-round recreational services.

Access to Transportation

Assure transportation needs of children with disabilities and their caregivers are met on a consistent and timely basis.

Key Findings For Young Adults with Disabilities

This next section reports on the findings associated with the transition and health care needs of young adults with special health care needs.

Young Adults with Disabilities

- Increased need for health and life insurance coverage for young adults creates financial strains on families and places young adults at-risk for poor health outcomes.
- Training of physicians to meet the health care needs of young adults with disabilities.
- Health care services are not consistent for young adults with special health care needs depending on the disability, age and geographical location. A system of care must be devised to adequately address the health care needs of young adults with disabilities.
- Independent living services are needed to help with housework, personal hygiene and activities for daily living.
- Increased communication is needed with adult medical providers to address prevention and on-going health care needs associated with young adults with special health care needs. Adult providers appear to be less connected to other service delivery systems, limiting referrals and coordination of services.

Transition Services for Young Adults.

- Increase educational and vocational training programs post-high school.
- Oriver education programs for children with special needs and support for obtaining own transportation.
- < Training to self-administer medication and to detect warning signs before crisis.</p>

- Appropriate respite care services for family of young adults with training on the selection of personal care attendants.
- Personal safety training to avoid assault and exploitation.

These findings are discussed in greater detail in subsequent chapters of this report.

Summary and Recommendations

These findings highlight the complexity of the system of care experienced by caregivers of children with special health care needs. The challenge these findings pose for the Title V program is to examine the current system of care and to develop strategies, policies and practices that effectively address the multiple needs of children with special health care needs and their families. The following recommendations are made in response to the children with special health care needs assessment.

RECOMMENDATIONS

- 1. Facilitate a multi-agency task force to address a coordinated system of care for CSHCN (to include, but not limited to, medical, psycho-social, education, and care giver supports) through a central point of entry and coordination of care.
- 2. Examine the system of respite care and develop recommendations to enhance the service.
- 3. Examine financial access for children with special health care needs, to include, but not limited to, provider reimbursement rates, insurance coverage, dental care, ancillary services [i.e. assistive therapies and technology, personal care attendants, and durable medical equipment]; medications, waivered services (e.g., skilled nursing), mental health, long term care in compliance with federal mandates, respite care, and housing.

- 4. Formalize a plan to ensure that all providers of services to children with special health care needs are appropriately trained to provide coordinated family centered, culturally competent, and community based care.
- 5. Facilitate the education and training of children with special health care needs and their families [to include, but not limited to, activities for daily living, post secondary education, vocational rehabilitation, self-advocacy, and independence and self-management].
- 6. Develop a transitional services system of care (to include, but not limited to, medical, psycho-social, and educational).
- 7. Evaluate the existing transportation systems for children with special health care needs and their families and develop recommendations to improve access to transportation services.

These recommendations provide the framework for meeting the health care needs of children with special health care needs and their families. Progress will be marked not by the ability to accomplish all the recommendations but, rather through the development of a careful and systematic plan that involves families and key stakeholders in every phase of the plan.

Chapter Two

Study Approach and Design

he study specifications were developed from these sources: a review of previous studies using focus groups, findings from the 1993 Statewide Needs Assessment of Children with Special Health Care Needs, key informant interviews and the guidance of the Advisory Group of this study. The following detailed requirements were jointly developed by the Title V staff and the Institute for Families in Society:

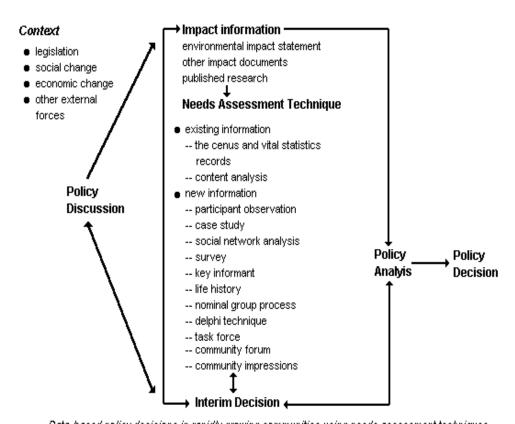
- The focus group participants were to consist of caregivers of children with special health care needs. The participants were to be a statewide representative sample of participants and non-participants in the 1994 Statewide Needs Assessment of Children with Special Health Care Needs.
- Caregivers could include: parents, family members, or legal caregivers of the children with special health care needs.
- The needs of young adults with special health care needs would be represented by the individual. Parental permission was obtained for participants under the age of eighteen.
- < All participation was voluntary. A Wal-Mart gift certificate worth ten dollars was provided to all focus group participants.</p>
- The study was to utilize three different measurement tools: focus-groups, mailed surveys with caregivers and young adults, and key informant interviews with key community-based and governmental agency stakeholders.
- Key informant stakeholders were to be selected from representatives of the following categories: health and social service agencies and organizations; health administrators; policy analysts; medical personnel (to include physicians and related occupations); family support organizations.
- Where possible, the study tools used questions from the 1994 Statewide Needs Assessment of Children with Special Health Care Needs. This was established to provide a framework from which to document system changes from the 1994 needs assessment.

The study methodology was to be carried out using standardized quality control procedures. In particular, emphasis was to be placed on procedures that protect the confidentiality of the participants and that would not exclude participants due to the format or language of the study tools.

The next section discusses in detail the study instruments and methods.

Methodology

The quality of information about a community is only as good as the technique or combination of techniques used by the research team. A single technique may be too narrow in the information it provides; using too many methods may be costly in terms of time and dollars. Different information-gathering techniques are appropriate for different needs. Figure 1 illustrates the multiple methods that can be used to guide community needs assessments.



Data-based policy decisions in rapidly growing communities using needs assessment techniques.

This

s assessment incorporated this framework to guide the study. However, it limited the needs assessment techniques from which to gather new information to three

strategies, i.e., survey, key informant interviews, and focus groups. The methodology was divided into the following four steps: 1.) a Advisory Committee was formed to provide the context for the needs assessment. 2.) a review of the literature was conducted from which to gather and document impact information. 3.) Under the leadership of the Title V program, a statewide committee was formed to develop a database documenting the prevalence of children with special health care needs in South Carolina, and . 4.) focus group and key informant protocols were developed to address five distinct participants in the 2000 Needs Assessment. Focus groups were conducted with following: participants from the 1999 SC Statewide Needs Assessment; families of children with special health care needs who did not participate in the 1999 needs assessment¹; young adults with disabilities; and, the physician Advisory Group of the Title V programs. Participation was completely voluntary. (See Attachment A - Focus Group and Key Informant Protocols). This next section provides a thorough discussion of the strategies selected for this needs assessment.

Focus Group Methodology

"A focus group is another name for a group interview or a group discussion, where the focus is on a particular topic of interest..." (Hawe *et al*, 1990: 174). As a method it is particularly useful when there is a power differential between participants and decision makers, and there is a need to explore throughly a particular topic with a defined population. A set of focus groups with adults typically consists of at least three interviews, each with six to nine participants, discussing a topic for up to two hours. The groups work best when the moderator, as well as the participants, aren't acquainted before the interview. The goal is to provide an open opportunity for people with a common interest to talk together so the researchers can determine their attitudes and opinions on the topic.

As a general rule, the focus groups did not last more than 2 and ½ hours and consisted of between six to ten individuals. The data was collected on butchers' paper -

¹Family Connections, Inc coordinated the recruitment of all families with special needs children who did not participate in the 1999 Needs Assessment. Additionally, they were responsible for coordinating the honoraria for participants and facilitating the identification of locations from which to conduct the focus groups.

allowing all participants to monitor what was being recorded and identify the information being generated by the group and captured by the facilitators. Tape recordings were used to capture the depth and generate quotes.

Caregivers of children with special health care needs were invited to participate in a focus group within fifteen miles of their home. Evening and daytime focus groups were scheduled to accommodate the schedules of the participants. Every effort was made to verify their participation twenty-four hours prior to the scheduled focus group. A gift certificate of ten dollars was provided to every participant and coordinated by Family Connections. A complete breakdown of focus groups by site and the number of participants is found in Table 1.

Table 1
Focus Group Participation Profile

County Site Location ²	# of Title V Participants	# of Non- Title V Participants	# of Young Adults ³	Total Number of Participants
Richland Coun	ty 2	4	7	13
Sumter County	4	1	NA	5
Charleston	9	5	NA	14
Greenville	9	6	NA	15
Title V Medica Advisory Gro		NA	NA	8
Total Participa	nts 32	16	7	55

A total of fifty-five individuals participated in the focus groups. Of those who participated, forty (or 73%) were identified as caregivers of children with special health care needs.

² One focus group was held in a county located within each of the SC Health Services Regions. The focus group for the Upstate Health Region was held in Greenville county. The group for the Northeastern Health Region was held in Sumter county. The Midland Health Region group was held in Richland County. The Coastal Health Region was held in Charleston County. The statewide Title V Medical Advisory met in Richland County at the central offices of the program.

³ Five of the young adults with special health care needs were recruited from students enrolled at the University of South Carolina and receiving services through the Student Office of Disabilities. Two of the seven were current recipients of services through the Title V program.

Survey Methodology

The survey technique is unique in that it is the only needs assessment method -other than talking to every citizen -- that has the potential of representing all individuals
in a defined population group. In this respect, it is a relatively inexpensive way to gather
information from a large number of people. If a survey is well-designed and
implemented, the results can be generalized to a larger population. The advantages of
this method consist of the following:

- A small, randomly selected sample can provide much information about a population. Can be inexpensive -- especially if volunteers are available to conduct the survey, or records and data exist from which to select participants.
- Can be used to survey an entire population and provide an opportunity for many persons to feel involved in decision-making process.
- Can be used to record behaviors as well as opinions, attitudes, knowledge, beliefs, and attributes.
- Useful if combined with another method -- such as participant observation or case study -- that will provide an interactive perspective or detail.

A mail survey was sent to non-focus group participants who indicated a desire to participate in the focus group. Due to the complex medical conditions of their children, the mail survey was restricted to individuals who could participate in the focus groups. A total of 42 surveys were mailed to caregivers of children with special health care needs. *The rate of return was 13 percent (or 13 returned surveys)*. All returned surveys were completely filled-out.

Key Informant Methodology

The key informant method is based on obtaining information, over time, from a stakeholder who is in a position to know the community well. The person or persons selected to be key informants must therefore have a broad knowledge of the community, its services, and its people. This methodology provides an excellent way to recover information about past events or ways of life that are no longer observable. The concept of community needs assessments offers a process by which an assessment of the community is undertaken. It establishes value judgements regarding the desired circumstances to be reached, and establishes a priority status of local needs. The Key

Informant Approach is effectively used <u>only</u> to gather information from residents whose professions allow them to be in a position to know the needs facing the community. The approach for this study was used in a brief interview.

A staff member with a social work background and the parent of a child with disabilities was selected to conduct the interviews. The key informant method requires sufficient time to build a good relationship between interviewer and the informant - - staff selection was critical to ensure the quality of the data. Overall, the value of the method is the type of data that can be elicited because of the communication and trust that develops between the two. The quality of information obtained is dependent on the ability to draw out the key informant's capabilities in perceiving and communicating the information.

Fifteen key informant interviews were completed with stakeholders. On an average, thirty minutes to an hour was spent with each participant. Due to scheduling conflicts, three of the 15 interviews (or 20%) were conducted via telephone using the same protocol. A complete breakdown of key informant participants by professional affiliation is found in Table 2.

Table 2
Profile of Key Informants by Affiliation
n = 15

Affiliation of Key Informant	Number of Respondents
Advocacy/ Family Organization	3
State Agency	9
Educational System	1
Medical Provider	1
Private Service Provider	1

Data Analysis Strategies

Focus Groups

Focus group data were collected on butchers' paper (i.e., easel pads). This process

allowed all the participants to monitor what was being recorded and to correct statements. Tape recordings were all transcribed for thematic analysis. Written responses were analyzed by the authors for themes using an inductive approach. Each individual independently read and coded the responses by theme, then met together to compare analyses. Minor differences and discrepancies were resolved through discussion. Summaries of the groups were compared to note items of concern (emerging themes) that surfaced in more than one group. Additional analysis was conducted with the typed transcriptions using EZ-Text, a qualitative data tool developed by the Centers for Disease Control. Full inter-rater agreement was reached on the themes listed in the key findings section of this report.

Key Informant and Survey Interviews

Key informant and survey interviews consisted of open-ended questions requiring similar methods of analysis to that employed with focus groups. The data were collected using a modification of the Doyle and Strauss Group memory method supplemented by audio recordings. All of the data were organized categorically by the question rather than chronologically according to the interview protocol. This method of analysis allowed for a summarization of the key issues which emerged from the groups. The key issues or themes were found consistently across all of the responses, regardless of the place of residence or occupation. EZ-Text computer-based qualitative tool developed by the Centers for Disease Control was used for data analysis.

Limitations of the Study Approach

As with any community needs assessment, this study has some limitations that must be taken into consideration when reviewing and applying the findings. The following are some of the questions that need to be answered:

- Were the focus participants representative of all caregivers of children with special health care needs?
- How accurate is the collected information?

The focus group and key informant methodologies rely heavily on the individuals understanding of issues and their willingness to self-disclose. Among some of the disadvantages to these methods include:

- Difficult to detect possible bias by original group facilitator was minimized by using two different formats for capturing the information (i.e., easel paper and audio recording). Inter-rater reliability procedures were developed to limit potential bias.
- Analysis categories may not accurately represent important ideas requiring that outlier information be carefully examined prior to excluding from the key findings.
- Possibility of recording irrelevant information, or of omitting relevant information; requires the ability to scan all the information.
- Time required to select the best informants and to build trust with key stakeholders may result in extending the time to complete the interviews.
- Personal relationship between researcher and informants may influence type of date obtained and bias the findings. To avoid this potential pitfall, the Principal Investigator of the project did not directly facilitate the focus groups or conduct the key informant interviews. Project staff with no direct knowledge of the participants were primarily responsible for data collection.
- Onta may be difficult to quantify unless well-organized immediately after each interview and focus group. As described in the previous section, care was taken to ensure that a summary of the key issues was developed within twenty-four hours of the activity.
- Should be combined with other methods, because representativeness of total community is difficult to achieve. It was important to include a diverse group of participants.

Few people can sense all the needs and concerns of all people in a community -the perspectives of those who are less visible may be overlooked. To assess the
limitations of these methods, key findings were presented to the Advisory Committee and
an independent faculty member of the Institute for Families in Society reviewed the
analysis framework, coding and key findings for accuracy and bias. It is our belief that
every effort was made to ensure a diverse representation of interests and the accuracy of
the data. As the next step, secondary data analysis linking respondents from the 1999
Statewide Needs Assessment and focus group participants will be examined to further
explore the reliability and validity of the reported findings. Secondary data analysis will
explore the correlation between such factors as age, type of disability, and the
information needs of all respondents. A separate report will be generated documenting a
sampling of the responses of focus group participants.

Chapter Three Results

The completed focus groups, key informants and telephone survey responses of 70 participants provided the data utilized for this chapter. The participants were a representative sample of individuals with disabilities and their caregivers, health care providers, and community stakeholders.

Focus Groups: Profile of Respondents

Focus group participants responded to the following questions:

- During the past 12 months, what do you consider to be the most important needs for your child/young adult and family?
- In the last five years, how have the needs of your child/young adult changed?
- What has happened to cause these changes?
- If you could develop a list of services that would help your child/young adult with special health care needs, what services would you consider to be the most important?

The phrasing of these questions were modified to reflect the responses of young adults participating in the focus groups. For purposes of this report, the responses from the caregivers and young adults are combined in the narrative.

Of the total respondents, forty (or 73%) were identified as caregivers of children with special health care needs. The ages of children and young adults with special health care needs ranged between 7 and 20. The average age for children with special health care needs was eleven years. The primary disabilities most frequently cited can be classified into one of three major categories; physical disabilities (46% or 22), neurological disabilities (20% or 9), and chronic health conditions (34% or 17). Most of the respondents reported being affected by more than one condition. Optional demographic information provided by the respondents indicated the following:

• Ethnic/Racial background: African American (60 %), Caucasian (25%), and Other (15%).

- The highest level of education completed by the caregivers: High School (30%), Some college (26%), Less than 12 years of education (14%), and College (11%).
- Fifty-five percent of the respondents reported annual incomes of less than \$30,000; of these, 44% reported incomes of less than \$20,000.
- Mothers were the most typical participants. Approximately, twothirds of the respondents were female heads of households. Over half of the caregivers worked either part-time of full-time.
- Respondents indicated great variability regarding access to health insurance for children and young adults with special health care needs. Approximately, one-quarter of the participants reported not having insurance coverage for their young adults with special health care needs.
- Eighty percent of children with special health care needs reported having access to health insurance through a combination of public programs (i.e., Medicaid and Title V).
- Caregivers of preschool age children reported a decline in services when their child moved from the early intervention system of care to the educational system.

Focus Group Findings for Children with Special Health Care Needs

The study documented the following needs:

• Financial Access to Health Care Coverage

- Increased insurance coverage across all age groups was identified as a need for the respondents. This was especially critical for families affected by welfare reform and SSI regulations.
- A need for increased number of Specialty Care Providers across the state willing to care for children with special health care needs.
- Equal coverage for mental health and physical disabilities was identified as an essential step in meeting the holistic needs of children with special health care needs. Caregivers identified

- increased need for behavioral and mental health services to help children adjust to their disabilities.
- Increased availability of home health services (Skilled Nursing and Respite Care) was identified as a critical need for respondents. Although home health services were available for Medicaid recipients, the regulations and limitation associated with this service did not provide the needed coverage. Similarly, skilled nursing care and respite care services are available on a limited basis through specialized or waiver programs that restrict eligibility to a small number of children.
- Expansion of coverage for therapies outside of educational settings. The eligibility requirements for therapies was far too limiting for children with complex medical conditions that require unlimited access to therapies. Additionally, caregivers pointed to a lack of training of physicians in prescribing therapies that might otherwise be covered by insurance programs.

System of Care

- Training of medical providers on assistive technology to address assessment and prescription needs is a needed intervention to adequately meet the needs of children with special health care needs.
- < Greater need for skilled child care and respite care services.</p>
 Respondents cited the need for child care and respite care services with providers adequately trained to meet the needs of children with special health care needs. This finding was especially critical for caregivers of children with complex medical conditions requiring specific care practices to ensure the health of the child.
- Increase coordination of care across agencies and providers to ensure continuity of care. Respondents mentioned the need to avoid duplicate applications and services across state agencies and

- the ongoing necessity for appropriate targeted case management services for children with complex medical needs.
- Increase coordination across funding streams to facilitate a comprehensive system of care. Several caregivers pointed to the high level of protection of "turf and their funding streams" across agencies limiting the ability of children to adequately meet their needs.
- < Greater need for school-based health care services and coordination with health care providers to ensure continuity of care and maximize the child's potential to learn. Overwhelmingly, caregivers mentioned the need for coordination between the educational system and health care providers. Failure to increase this coordination results in children being inadequately placed in classrooms or to self-contained classrooms.</p>
- Reduction of "red tape" by creating a central point of access to public health services. Consistently, caregivers expressed frustration with the amount of time wasted in obtaining services for their child with special needs due to "agency red tape". As an example, evaluations conducted by one state agency are often not accepted by another wasting both resources and delaying the health care needs of the child.
- Eliminate geographically-based access to health services disparities. Respondents pointed to disparities in health care access and services for rural residents across the state. As an example, they cited the lack of specialty care clinics located in rural counties requiring excessive travel for families.
- Increase vocational opportunities for children with special heath care needs. As a general rule, respondents expressed the lack of available vocational options for children with special health care needs. Among the key reasons cited was the lack of involvement

of SSI and vocational rehabilitation services to facilitate their transition to employment and post-high school educational training

Access to Social Support and Recreational Services

Increase access to family support and year-round recreational services.

Access to Transportation

Ensure transportation needs of children with disabilities and their caregivers are met on a consistent and timely basis.

Focus Groups Key Findings for Young Adults with Disabilities

This next section reports on the findings associated with the transition and health care need of young adults with special health care needs.

Young Adults with Disabilities

- Lack of health and life insurance coverage for young adults creates financial strains on families and places young adults at-risk for poor health outcomes.
- < Adult physicians are not adequately trained to meet the health care needs of young adults with disabilities resulting in a major gap in the availability of health care services.
- Health care services are not consistent for young adults with special health care needs depending on the disability, age and geographical location.
- Increased access to independent living services is needed to help young adults with housework, personal hygiene and activities for daily living.
- Increased communication is needed with adult medical provider to address prevention and on-going health care needs associated with young adults with special health care needs. Adult providers appear to be less connected to other service delivery systems, limiting referrals and coordination of services.

• Transition Services for Young Adults.

< Increase educational and vocational training programs post-high school.

- Oriver education programs for children with special needs and support for obtaining own transportation.
- < Training to self-administer medication and to detect warning signs before crisis.</p>
- < Appropriate respite care services for families of young adults, with training on the selection of personal care attendants.
- < Personal safety training to avoid assault and exploitation.

Key Informants: Profile of Respondents

Key informants responded to the following set of questions:

- In your opinion, what are the current gaps in the system of care that affect children with special health care needs?
- Over the last five years, what impact has the shift in Medicaid coverage made on financial barriers to care and services delivered by state and local public health agencies?
- What impact has the move to managed care delivery systems had on services for children with special health care needs?
- If the system of care could be redesigned, what elements would need to be included?
- How could existing services be improved for children with special health care needs and their families?

For purposes of this report, the responses from the key informants are combined with the Title V Medical Advisory Focus Group participants. This was done to reflect the similarity of concerns and identification of key issues between the key informants and the medical providers. The profile in this section is limited to key informants and does not reflect the backgrounds of the Title V Medical Advisory Group.

Of the key informants, a breakdown of their affiliation is as follows:60 percent identified themselves as affiliated with state agencies (9 out of 15); seven percent were connected to an advocacy or family support agency, with the rest of the participants affiliated with private providers or the educational system. As a group they averaged 21 years of experience working with children with special health care needs. The

respondents were Caucasian (15 out of 15) and primarily male (9 out of 15). They were a representative sample of key stakeholders and policy makers in the current system of care for children with special health care needs.

Key Informants Findings

In the past five years, the respondents cited increased Medicaid coverage as benefitting children with special health care needs by expanding their coverage, number of prescriptions, and access to primary care providers. However, the gains made through this expansion did not adequately anticipate the number of children entering the system, the availability of providers willing to serve Medicaid- eligible children, and the fee reimbursements for specialty care providers to adequately meet the needs of children with special health care needs. As a result, a system has been created with greater consumer expectations for services with an adequate infrastructure to meet those needs. Caregivers participating in the focus groups were in agreement that in many ways increased access to health care had improved for children with special health care needs and their families. They expressed continued concerns over inadequate coordination of care, disparities in the provision of healthcare in rural and medically underserved counties and frustration with the inadequacy of the system to effectively meet the holistic needs of children with special health care needs. *Among the key findings impacting the current system of care are the following:*

- Caregivers of children with special health care needs continue to experience difficulty in accessing services due to lack of coordination between providers and available funding streams.
- Lack of transportation continues to be a major barrier to accessing needed services complicated by the lack of services located in rural and medically underserved counties.
- Informational needs of families continue to go unmet due to a lack of foci on the life span needs of the child and family. This need has become critical with the shift to family support services which do not adequately address the target case management needs of children with special health care needs. Further complicating this situation is the divergent philosophy of care

- coordination among the different agencies providing services to children with special health care needs and their families (e.g., person-centered care versus family-centered care).
- Increased access to heath-related professionals has not translated into adequate services for children with special health care needs in the school system. Gaps still exist in the school system for nursing, occupational, physical, speech and applied behavior therapists to adequately meet the needs of children with special health care needs. The current emphasis on school readiness raises expectations that children with special health care needs can, through community interventions, become ready for school without increasing funding for school districts.
- There does not exist an adequate system of care to address the needs of children dually diagnosed with medical and mental health needs. The identification of these children requires early identification and the provision of timely behavioral interventions.
- Low Medicaid reimbursement rates associated with specialty care services is resulting in eligible children not having access to needed services. As an example, the respondents cited the current shortage of endocrinologists and the ability to recruit these providers with the current reimbursement rates.
- Family support services continue to be inadequate to address the multiple needs of children with special health care needs and their families. As an example, there continues to exist a lack of child care, respite care, after school, and summer programs for children with special health care needs. These services have become critical for many working families struggling with changing regulations for SSI and the impact of welfare reform requiring them to find employment.

- A system does not currently exist that adequately addresses transition from school to work or home to school for children with special health care needs. This is resulting in inadequate opportunities for children and young adults with disabilities to reach their maximum potential.
- Skilled nursing care services constitutes a major gap in the service delivery system for children with complex medical conditions. The current waiver program is not inclusive of all children with special health care needs requiring skilled nursing care services.
- Lastly, respondents cite that the current system of care for children with special health care is reactive and not proactive. As a result there is no little emphasis on prevention efforts and planning to adequately meet the needs of children with special health care needs and their families throughout the life span.

Summary

In the past five years targeted policy changes have resulted in increased access to services for children with special health care needs and their families - - there is still much to be done. The underlying factor in all of the identified barriers is the need to provide services which are consistent, timely and appropriate to meet the changing and complex needs of children with special healthcare needs and their families throughout the lifetime of the child. This requires that major policy changes be implemented that eradicate disproportional differences between needed and available services, differing funding streams, and the coordination of services for all children.

Chapter Four

Conclusions and Recommendations

The Title V needs assessment of children with special health care needs provides a point from which to reflect on the changes in the system of care. Since 1999 major initiatives have been launched to enhance the quality of life for all children in South Carolina. Among these changes are included the following:

- Overview of South Carolina's Children's Health Insurance Program. South Carolina started considering how to restructure its Medicaid program in 1995, when Congress considered making Medicaid a block grant program. Partners for Healthy Children (PHC) began enrollment effective August 1, 1997. During the period of August 1, 1997, through September 30, 1998, South Carolina increased its Medicaid net caseload of children by 60,500 through the PHC program.
 - < Prior to Title XXI, South Carolina's Medicaid program covered children age 0-1 and pregnant woman with family incomes at or below 185 percent of the Federal Poverty Level (FPL); children age 1-5 with family incomes at or below 133 percent of FPL; children age 6-13 with family incomes at or below 100 percent of the FPL; and children age 14-18 with family incomes at or below 48 percent of the FPL. Under Title XXI, effective August 1, 1997, South Carolina extended eligibility to children age 1 through 18 with family incomes at or below 150 percent of the FPL and maintained coverage to pregnant women and children age 0-1 with family incomes at or below 185 percent of the FPL. HCFA approved South Carolina's CHIP application on February 18, 1998, with the effective date retroactive to October 1, 1997. One of South Carolina's strengths in having a successful outreach program is its strong history of public and private partnerships. Most of South Carolina's partnerships are informal, with the exception of the formal partnership with the Department of Health and Environmental Control (DHEC) and local health departments.

- Changes in South Carolina's MCH. South Carolina has a strong integrated public health system consisting of 46 counties and 13 districts, where the public health employees are also State employees.
 - The public health system, together with the private system, have been working together to provide all children with a "medical home." A child's "medical home" provides comprehensive medical and preventive care to supplement a child's primary health care. These partnerships work together and complement each other's expertise. The physician provides medical services and the public health sector provides preventive, as well as family support services. The Department of Health and Environmental Control, South Carolina's public health provider, has created these partnerships to ensure there are no gaps in a child's health care service by establishing Family Support Services (FSS). The first group of providers to accept the "medical home" concept were obstetricians and gynecologists; DHEC has expanded this initiative with pediatricians and family practitioners.
 - OHEC Family Preventive and Rehabilitative Support Services were expanded to be provided by a team of professionals, including public health nurses, social workers, nutritionists, health educators, dieticians, and public health assistants. Services provided include: comprehensive assessments, service planning, patient monitoring/tracking, and referrals by an interdisciplinary team of experts skilled in the provision of services in a community setting.
- DHHS Physicians Enhanced Programs. The Physicians Enhancement Program (PEP) through the Medicaid program allows physicians to receive an enhanced capitated rate for providing primary care services through a "medical home." There are no risk factors for participating physicians; hospital and specialist referrals are paid on a fee-for-service basis.
 - Another DHHS program created was the Healthy Options Program (HOP). In HOP, physicians and physician groups contract to take children and provide them with a "medical

home." For each "medical home" provided, the physician or physician group receives an additional \$10 in per month capitated payments. Built into the design of HOP is the requirement that the physician or physician group will refer to DHEC any problems detected that require family preventive and rehabilitative support services (there is language in DHHS' contract with DHEC to this effect). A number of the larger physician practices in South Carolina have incorporated public health staff into their systems. The physician practice provides computers and space and DHEC staff receive referrals on-site enabling them to provide direct inhouse support for families. DHEC plays a key role in encouraging more doctors to provide medical homes through the Medicaid program.

- Lastly, DHEC has helped to develop some 76 partnerships through PEP and HOP. The initial partnerships evolved around the provision of EPSDT and has expanded to related medical care services.
- Medicaid Managed Care Programs. Since 1995, the penetration of managed care programs has increased to 12 percent. The notable exception is Greenville county with a market penetration of 14 percent.

In spite of these changes in the system of care, the key findings of this study indicate that children with special health care needs and their families continue to have unmet needs. The following recommendations are made based solely on the findings of this study with consumers and key stakeholders.

Recommendations

1. Facilitate a multi-agency task force to address a coordinated system of care for CSHCN (to include, but not limited to, medical, psycho-social, educational, and care giver supports) through a central point of entry and coordination of care.

- 2. Examine the system of respite care and develop recommendations to enhance the service.
- 3. Examine financial access for children with special health care needs, to include, but not limited to, provider reimbursement rates, insurance coverage, dental care, ancillary services [i.e. assistive therapies and technology, personal care attendants, and durable medical equipment]; medications, waivered services (e.g., skilled nursing) mental health, long term care in compliance with federal mandates, respite care, and housing.
- 4. Formalize a plan to ensure that all providers of services to children with special health care needs are appropriately trained to provide coordinated family-centered, culturally competent, and community-based care.
- 5. Facilitate the education and training of children with special health care needs and their families [to include, but not limited to, activities for daily living, post secondary education, vocational rehabilitation, self-advocacy, and independence and self-management].
- 6. Develop a transitional services system of care (to include, but not limited to, medical, psycho-social, and educational).
- Evaluate the existing transportation systems for children with special health care needs and their families and develop recommendations to improve access to transportation services.

These recommendations provide the framework for meeting the health care needs of children with special health care needs and their families. Progress will be marked not by the ability to accomplish all the recommendations, but rather through the development of a careful and systematic plan that involves families and key stakeholders in every phase of the plan.

ATTACHMENT A

Children with Special Health Care Needs Needs Assessment 2000 Study Key Informant Protocol

Developed for:

Children's Rehabilitative Services Title V Program

South Carolina Department of Health and Environmental Control

by:

Institute for Families in Society
University of South Carolina
937 Assembly Street - - Carolina Plaza
Columbia, SC 20208
803-777-9124 (Voice)
803-777-1793 (Fax)

Background

One of the difficulties in assessing the needs of children with special health care needs is that in many instances, data is not available to document the impact of policies on the major concerns of these children and their families. One source of information is key leaders in the community who are familiar both with health concerns and with programs that are already providing services. This protocol will be used to collect information from community leaders regarding their views of the policy issues of concern to children with special health care needs and their families.

Who Are The Key Informants

A minimum of 15 key individuals in South Carolina who are familiar with the health care system and who are knowledgeable about children with special health care needs and their families. This would include individuals involved in direct care as well as those working in administration and health policy. Individuals will be selected from each category:

- Directors of health and social service agencies and organizations⁴
- State health administrators⁵
- Policy analysts⁶
- Physicians; nurses; health educational; service providers⁷
- Family Support Organizations ⁸
- Caregivers of children with special health care needs⁹

⁴ SC University Affiliated Program (Ferrante); SC Protection and Advocacy (Prevost)

⁵ SC DHEC (Commissioner); Title V Program (Price); SC DHHS (Jones and Thomas); SC DDSN (Kelly); SC Vocational Rehabilitation (La Rosa); SC DODAS (Francis); SC Dept. of Education (Spann)

⁶ SC Children's Office (Waites); SC Budget & Control Board (Holmes); Alliance for SC Children (Rushton)

⁷ USC Medical School Department of Pediatrics (Derrick); Greenville Children's Hospital (Schmidt)

⁸ Family Connections (Ginsberg); Caring Connections); ProParents

⁹ Title V Program Parent; SC DDSN

I. Introduction to the Interview

- Explain that you are working with the Institute for Families in Society to conduct a follow-up study under contract with the SC Department Health and Environmental Control, Children's Rehabilitative Services Program (Title V). The purpose of the study is to examine the health concerns of children with special health care needs and their families. One part of the needs assessment is to speak with key community leaders to get their opinions regarding policy shifts that affect children with special health care needs and their families.
- Begin by requesting some information about the person you are to interview.

П.	Descrip	tion of the Pe	erson Being Interviewed		
1.	Sex:	(a) Female	(b) Male		
2.	Race (/	one) (a)	(a) White		
	(b) Black / African American				
	(c) Asian/Pacific Islander				
		(d)) Hispanic/Latino(a)		
		(e)	Other (specify):		

- 3. The person being interviewed is primarily a:
 - (a) Directors of health and social service agencies and organizations
 - (b) State health administrators
 - (c) Policy analysts
 - (d) Physicians; nurses; health educational; service providers
 - (e) Family Support Organizations
 - (f) Caregivers of children with special health care needs
- 4. How many years has this person been active/involved in working with issues that affect children with special health care needs and their families?

5. Provide a brief profile of the agency, position and scope of work that the interviewee represents/holds:

Interview Questions (Read out loud items in bold print)

- 1. In your opinion, what are the current gaps in the system of care that affect children with special health care needs?
- 2. Over the last five years, what impact has the shift in Medicaid coverage made on financial barriers to care and services delivered by State and local public health agencies?
- 3. What impact has the move to managed care delivery systems had on service delivery and the availability of services to children with special health care needs, women and infants, and children?
- 4. In your opinion, what impact has financial access (private insurance, risk pools, State Insurance programs, child health initiatives) had on children with special health care needs?
- 5. If the system of care for children with special health care needs could be redesigned, what elements would need to be included to effectively address access to health care for this population?
- 6. How could the existing services be improved for children with special health care needs and their families?

Focus Groups with

Parents and Care givers of Children with Special Health Care Needs: Title V CRS Needs Assessment

Project funded by:

SC Department of Health and Environmental Control Children's Rehabilitative Services – Title V Program

Recruitment Packet Contents:

- 1. Copy of an introductory letter to caregivers of children with special health care needs.
- 2. Informed Consent to Participate Forms to be signed by all focus group participants
- 3. Most Frequently Asked Questions forms to be used by contact person
- at focus group location sites
- 4. Invitational reminder sheets to be distributed to consenting participants

INVITATIONAL DRAFT LETTER TO PARTICIPANTS

Name

Address #1

Address #2

Address #3

Dear

Thank you for agreeing to participate in a focus group of six to eight parents or care givers to explore their thoughts, feelings, and reactions toward improving the care of children with special health care needs. The objectives of the *Children's Rehabilitative Services (CRS) Needs Assessment Follow-Up Study* are to identify parents' or caregivers' recommendations for improving the care of children with special health care needs as well as the unmet needs of parents and care givers and their children. The study will help provide an understanding of the policy changes to the system of care impacting children with special health care needs for the period between 1994 and 1999. A focus group is designed to help facilitate discussion in a casual, nonthreatening manner for all participants. It is our expectation that the compiled information obtained from the focus groups will help you and ultimately the parents and care givers of children with special health care needs.

Enclosed is a packet of information for you to review. Your participation is very important to this project. The Institute for Families in Society at the University of South Carolina will be conducting these focus groups. Please do not hesitate to contact Ana Lopez De Fede at 777-5789 (Principal Investigator) or Jeannine Salone (Research Associate) at 777-7906 at the Institute for Families in Society with any questions about your participation.

They will be will calling you within the next two weeks to schedule the time of focus groups. On behalf of our staff and the families we serve thank you for supporting this effort.

Sincerely,

Linda Price, Director

CRS – Title V Program

INFORMED CONSENT TO PARTICIPATE FORM

The University of South Carolina on behalf of the SC Department of Health and Environmental Control Children's Rehabilitative Services Program (CRS) is leading eight discussion groups (focus groups) throughout the state. You are being asked to participate in one of these groups to identify what you consider are the most important needs and services for children with special health care needs and their families. In this discussion, you will be asked to share with other parents and care givers of a child with special health care needs your experiences regarding any unmet needs you may have to care for your child. You will be asked to give your ideas and recommendations to improve the current system of care so programs and services effectively meet the needs of children with special health care needs and their families.

All the information that you and everyone is this group will share today is confidential. Confidentiality means that your name will never be used with the information discussed here. Your participation in the discussion is voluntary; you may wish to participate in all or some of the discussion. There are no penalties if you decide not to participate at all. There are no risks for participating in this discussion. Your participation will not affect your job, or your educational classes (if you are currently in school), or current or future services you are receiving. We will tape the discussion and will only use the recorded information to supplement the compiled information. We will destroy the taped information at the completion of the project.

There is only one type of information that is not confidential. We want to let you know that we are required by South Carolina law to report to the Department of Social Services any discussion about child abuse and neglect that currently places a child at risk of abuse. *However, these group discussions will not deal with child abuse and neglect issues.* The information you share with us will only be used to identify children and families' unmet needs and to make recommendations about how to improve the way services are provided to children with special health care needs and their families in South Carolina.

If you have questions or concerns, you may contact the following individuals at the University of South Carolina: Jeannine Salone at (803) 777-7906 or Ana Lopez De Fede at (803) 777-5789.

Please sign and date this form to acknowledge that you have read and understand this consent form:

Signed			
Date			

EACH PARTICIPANT SHOULD BE GIVEN A COPY OF THIS CONSENT FORM.

Frequently Asked Questions

What is a focus group?

A focus group is a discussion when a small group of people can talk about their common experiences on a particular subject or question. We will be asking you to tell us about your thoughts, feelings, and ideas in regard to improving the care of children with special health care needs.

We value your experience as a care giver of a child with special needs. We want to know if there are any unmet needs that your child with special health care needs and your family have and wish to share with us. All identified unmet needs will be documented and recommendations will be made to the appropriate care providers to address those needs.

Will you use my name?

Why conduct a focus group?

The information collected from the focus groups will be used to improve the care of children with special health care needs. No information will be used that can identify you by name, address or any other personal facts.

Why was I selected?

You were selected because you are a care giver of a child with one of the following conditions (i.e., Spina Bifida, Cystic Fibrosis, Diabetes, Sickle Cell, Down Syndrome and Tracheostomy) who participated in the 1994 Children's Rehabilitative Services Needs Assessment Study; or you are community leaders with organizations serving children with special health care needs and their families; or you are a care giver who met the following inclusion criteria and did not participate in the 1994 Children's Rehabilitative Services Needs Assessment Study: *a) The child*

has a chronic disability or illness with a physical health impairment; b) The child is between the
ages of 5 and 18 years; and c) the is child is living at home at the time of the study.
How much time will it take to conduct the focus group?
The focus group will take approximately 2 to 2½ hours. The group may take less time, however
we ask that all participants be prepared to stay for at least 2 hours.
Is there a cost for participating in the group discussion?
There is no cost involved for participating in this focus group discussion?
When will the focus group session be taking place?
The focus group will take place on (Date)at this (Time)

You are invited to join a Discussion Group about Caregivers and Parents of Children with Special Health Care Needs.

Come and join other care givers and parents of children with special health care needs to talk about the best ways to improve health care provided to your children.

Date:		
Time:		
111110		
-		
Location:	 	

Come and express yourself! Your opinions are valuable and make a difference in your child's life!

Light refreshments will be served during the discussion session.

Focus Group Questions

- 1. During the past 12 months, what have been your child and family's biggest needs? In thinking about this, please consider <u>only the top five</u> things that your family still needs?
- 2. In the last five years, how have the needs of your child and family changed?
- 3. What do you think has caused these changes?
- 4. If your were to design a system of care that meets the needs of children with special health care needs and their families, what kinds of programs or services would be part of that system?

South Carolina Statewide Needs Assessment of Young Adults with Special Health Care Needs Year 2000



South Carolina Department of Health and Environmental Control



The Department of Health and Environmental Control
Children Rehabilitative Services
1751 Calhoun Street
Columbia, SC 29201-2606
(803) 898-0742 or 1-800-868-0404

Final Report May 2000

South Carolina Statewide Needs Assessment of Young Adults with Special Health Care Needs Year 2000

Report Prepared By:

Khosrow Heidari
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Bureau of Epidemiology

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Executive Summary

To assess the unmet needs of the 18-21 year old CRS population, a mail-in survey was sent to patients who had to received CRS services. These were all Children with Special Health Care Needs (CSHCN) who were discharged from CRS during 1995, 1996 and 1997 due to ineligibility by age (eighteen years and greater). In this survey all families of CRS graduates were asked to respond for the patients as appropriate to avoid possible low response rate associated with the method of mail-in self administered questionnaire. A list of 1033 names and addresses from the CRS clients' archive was obtained to conduct the survey. We made three attempts to reach everyone, but, 272 was undeliverable due to either incorrect, moved with no or expired forwarding addresses. But Of those correspondents that made it to our target population (761) a large number went unanswered 480 (63%), 10 (1.3%) refused, one deceased and three incomplete. We received 267 (35%) completed questionnaires.

CRS Gradute Young Adults' Characteristics:

- Average age of young adults was 20 years
- 63% (or 155) Black,
- 57% (or 152)of responses were completed by the parent of the young adult,
- 52% (or 136) Female,
- Median household income was \$6,000,
- 8% (or 21) were married,

The expressed needs of these young adults are as follows:

A. Access to Primary and Sub-Specialty Care:

- Even though the majority of young adults (59% or 149) surveyed said they are getting the type of medical care that they need, 41% (or 103) declared their medical care need is unmet. Most of these are younger black female, who live with their family of 3 or more members,
- 76% of 264 said they have seen a doctor for their medical care during the past 12 months.
- Most (55% of 222 who answered this question), saw a general practitioner or a family doctor,
- They saw this doctor in a private office (57% of 222), or in a hospital clinics (32%), or Emergency Room (22%),
- 75% of 222 consider the doctor that they saw for their medical care during the past 12 months as their primary care doctor,

Possible areas of concern regarding access to care:

• 19% of 171 expressed they could not get an appointment with a doctor,

- 21% of 175 said doctors are not familiar with their health condition,
- 53% of 218 indicated they were unable to pay for their health care cost,
- 29% of 188 said they could not keep their doctors' appointment because of a transportation problem.

Dental health care needs (of 263 who answered the dental health care need question: 69% expressed some kind of need)

- 23% (or 44) need dental braces,
- 87% (or 165) need regular dental care and,
- 13% (or 24) some kind of oral surgery,
- 69% (or 144) of 208 said they need assistance paying for their dental health care needs.

B. Medication Need:

- 75% (or 48) said they either had no money, no Medicaid, or no insurance to pay for medications,
- 29% (or 19) said medications were not covered by insurance,
- 9% (or 6) said they had unpaid bill,
- 8% (or 5) said pharmacy did not take Medicaid,
- 12% (or 7) indicated other reasons which ranged from "refuses to take medicine" to "don't need it."

C. Health Care Coverage:

- 44% (or 99) said they had difficulty getting health care insurance,
- 11% (or 25) said it was somewhat difficult.
- 20% (or 44) said it was somewhat easy and,
- 25% (or 55) said it was easy,

Of the 265 responses:

- 49% (or 131) have Medicaid card,
- 34% (or 90) have No coverage,
- 12% (or 34) have Private health insurance coverage,
- 8% (or 21) enjoy Medicare coverage,
- 5% (or 15) have other,
- 2% (or 5) CHAMPUS/ CHAMPUS VA

D. Diet and Special Nutrition Need:

264 yong responses to questions concerning diet revealed:

- Only 15% (or 40) had seen a nutritionist or dietitian during the past 12 months,
- 83% (or 219) had not seen anyone during the past 12 months,
- 2% answered "Don't Know."

In response to questions concerning special diet:

- 11% of 266 respondents said they are on some kind special diet,
- 10% (or 26) of 260 responses indicated a special drink or food for their diet had been prescribed, but 73% (or 19) of those were using it.

E. Access to Support System:

- 25% of 261(or 64) said they had seen a social worker or psychologist during the previous twelve months, of whom mostly %69 (or 44) saw this person in a hospital, doctor's office or health department,
- 35% of 255 (or 90) respondents said they do not spent as much time with others as they like,
- 28% of 255(or 72) respondents said they have friend with long term health care conditions.
- 24% of 259 (or 61) respondents indicated they are member of an organized group (e.g. Kiwanis Club) or a support group (e.g. Young Adults with Diabetes) or a church group,

F. Level of Independence:

- Among 267 responses 85% said the young adult lives with family; 8% are married, 7% live alone, and 8% have other living arrangements.
- When asked what may help increase their **independence**, among 267 responses:
 - 40% answered getting a job,
 - 34% answered getting a driver's licence,
 - 21% answered managing money,
 - 21% answered college education
- When asked about **total dependence** on others for ordinary activities:
 - 7% of 252 could not walk or move around,
 - 8% of 251 could not move (like from chair to a bench),
 - 6% of 251 could not communicate or talk,
 - 8% of 250 could not write,
 - 9% of 252 could not groom,
 - 10% of 192 could not use special equipment,
 - 12% of 234 could not take medication,
 - 7% of 251 could not tell when healthy or not.

G. Transitional Services:

Of 246 responses 14% (or 34) indicated they did not receive any transitional services from any sources:

- 79% (or 195) indicated they had received transitional service from school, mostly for securing employment (59), College (48) and Job training(48),
- 61% (or 150) indicated they had received transitional service from other sources, mostly for independent living (44) securing employment (26), College (25) respondents,
- 46% (or 114) indicated Vocational Rehabilitation Services provided them with transitional service, mostly for securing employment,
- 33% (or 82) indicated DHEC (CRS) provided mostly transition to adult care (55),
- Very few 6% (or 14) recognized any advocacy organization play any transitional role prior to their 18th birthday.

Year 2000 Needs Assessment of CSHCN

Introduction:

According to the Title V Block Grant requirements, "The State must prepare a statewide needs assessment every 5 years that shall identify (consistent with health status goals and national health objectives) the need for:

- preventive and primary care services for pregnant women, mothers and infants,
- preventive and primary care services for children,
- services for CSHCN ."

South Carolina has assessed the needs of the Children with Special Health Care Needs (CSHCN) population and their families. A Needs Assessment Team (NAT), composed of representatives from CRS, MCH Epi, DHEC Districts and the USC Institute for Families in Society, proposed the following approaches:

- 1. Community Focus Group(Follow up Study): the main objective of this approach was to follow-up on the '95 survey results of CSHCN and explore other unmet needs. We administered eight community focus groups in four DHEC regions. We collaborated with parent organizations as well as local and district DHEC staffs. The full report may be requested from CRS central office after June, 2000.
- **2. Provider Survey:** To assess the unmet needs of all CSHCN, particularly CRS graduates, a self-administered assessment tool was mailed to all SC pediatricians and pediatric sub-specialists. The full report will be available from the CRS central office after June, 2000.
- **3. CRS Graduate Survey:** To assess the unmet needs of the 18-21 year old CRS population, a mail-in survey was sent to CRS graduates who used to receive CRS services. These are all CSHCN who were discharged from CRS during 1995, 1996 and 1997 due to ineligibility by age. In this survey all families of CRS graduates asked to respond for the patients as appropriate to avoid possible low response rate associated with the method of mail-in self administered questionnaire. The NAT composed ten topics (domains) from which to obtain information from these children. Then, a set of items (questions) were developed to research each of the topics [see Appendix I for a copy of the questionnaire with number and percentage of responses].

Communications with the Young Adults and Their Families:

A list of 1033 names and addresses from the client archive was obtained to conduct the survey CRS graduates [see Figure 1. for a Map of the number of CRS graduates who potentially covered respond to the survey]. To verify addresses for mailing the questionnaire, a letter and a self addressed and stamped post card were mailed to all potential families. This vehicle enabled us to gain updated addresses and information about the families arrangement. Our respondents returned

200 cards indicating their willingness to participate in the survey from 1033 mailed cards. This was our first sign that we may need to deploy a small motivational reward for completing and returning the survey (i.e. a \$5.00 gift certificate was promised and mailed after the completed questionnaire was received).

Figure 1 depicts the distribution of 1033 young adults' county of residence statewide. We considered this as our potential target population. The counties with high population density contained more of CRS young adults as they were expected.

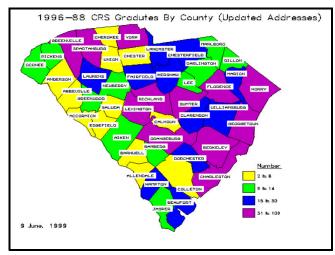


Figure 1. Potential contacts

Responses:

Of correspondence delivered to our target population (761) a large number went unanswered 480 (63%), 10 (1.3%) were refused, one client was deceased and three questionnaire were incomplete. We received 267 (35%) completed questionnaires, [see Figure 2. for the distribution]. Initially, 272 letters were returned either with incorrect addresses or notification of moved with no or expired forwarding addresses.

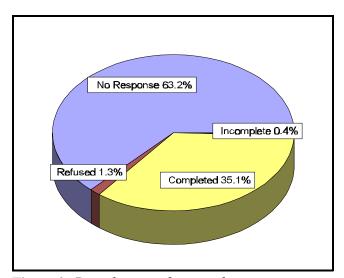


Figure 2. Distribution of respondents

Respondents' Characteristics:

- Average age of young adults was 20 years,
- 87% (or 230) completed high school
- 63% (or 155) were Black,
- 52% (or 126) were Female,
- 8% (or 21) were married,
- 57% of responses were completed by the parent of the young adult,
- Median household income was \$6,000. [For the income sources see Figure 3]

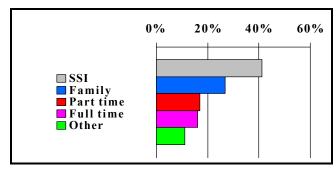


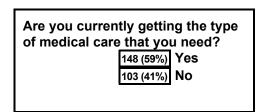
Figure 3: Respondents source of income

A. Access to Primary and Sub-Specialty Care:

In this section we explored access to primary and sub-specialty care for young adults who responded to the 1999 survey. Most young adults with special health care needs were under the care of more than one specialist, particularly if they had multiple disabilities. They should have a medical home where all their medical care is coordinated. Unfortunately, in reality, care is often fragmented and not coordinated through a primary care physician to assure preventive and medically necessary health services.

A total of 267 completed questionnaires were analyzed. We found:

• Even though the majority of young adults (59% or 149) surveyed said they are getting the type of medical care that they need, 103 (41%) declared their medical care need are unmet. Most of these are younger black females who live with their family of 3 or more members.



About the services received:

- 76% (or 196) of 264 said they have seen a doctor for their medical care during the past 12 months.
- Most (59% of 196) saw a general practitioner or a family doctor.
- 49% of 196 went to their specialist to seek medical care during the last year.
- They saw their doctors in a private office (59% of 196), in a hospital clinics (33% of 196), or Emergency Room (17% of 196).
- 76% of 196 consider the doctor that they saw for their medical care during the past 12 months as their primary care doctor.

Hallum, Ann "Disability and the Transition to Adulthood: Issues for the Disabled Child, the Family, and the Pediatrician"; <u>Current Problems in Pediatrics</u>, Jan. 1995 Pp 12-50.

When asked about their areas of concern during the 12 months prior to the survey date:

- 19% of 171 expressed they could not get an appointment with a doctor.
- 21% of 175 said doctors were not familiar with their health condition.
- 53% of 218 indicated they were unable to pay for their health care cost.
- 29% of 188 said they could not keep their doctors' appointment because of a transportation problem.

During the past 12 months, which of the following situations have been a problem for you? (check all that apply)					
Could not get an appointment with a doctor,					
32 (19%) Yes 139 (81%) No					
Doctors are not familiar with your health condition,					
37 (21%) Yes 138 (79%) No					
Unable to pay for your health care cost					
115 (53%) Yes 103 (47%) No					
Keeping doctors' appointment because of transportation					
55 (29%) Yes 133 (71%) No					

Even as a young adult, the majority (181 or 69%) of the survey respondents indicated they have **dental** health care needs of whom:

- 23% need dental braces,
- 87% need regular dental care and,
- 13% need some type of oral surgery,

In response to whether they need **assistance with paying** for their dental health care needs:

• 69% of 208 said they did.

In response to whether they were refused any services they felt they needed, since they tuned 18 years of age, majority (181 or 85%) of the respondents said "no." Those who responded "yes" to this question further indicated that they were refused the service because:

- they did not have any money, Medicaid, or insurance (54%),
- the service was not covered by insurance (32%),
- the provider did not take Medicaid (21%).



According to 1995 Statewide Needs

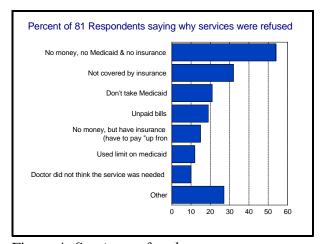


Figure 4: Services refused

Assessment 13% of children with special health care needs did not visit a primary care doctor during the 12 months prior to the interview. As these children grow to adulthood, we found 24% of them had not see a doctor for their medical care during the previous 12 months. Of those who have seen a doctor within last 12 months 22% did not consider him/her as their primary care doctor. Ideally, every child or young adult with special health care needs should have access to a primary care provider whom he/she could visit as needed.

B. Medication Need

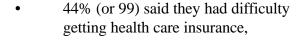
CRS assists families of CSHCN with prescription medication purchases. Often the young adults' coverage does not pay for all necessary prescriptions. From the 267 young adults and their families we found 24% (64) needed medication but could not get it of whom:

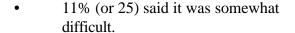
- 75% (or 48) said they had no money, no Medicaid & no insurance,
- 29% (or 19) said the medication was not covered by insurance,
- 9% (or 6) said they had unpaid bill,
- 8% (or 5) said the pharmacy did not take Medicaid,
- 12% (or 7) indicated other reasons which ranged from "refuses to take medicine" to "don't need it."

C. Health Care Coverage

As a young adult turns 18 years of age, his/her eligibility for most of the public health sources of health care coverage becomes a focus for the family. Often misinformation or lack of sufficient information about public assistance causes unnecessary family anguish.

We asked, during the past 12 months, how has getting health insurance coverage been? From 223 who responded (see figure 5):





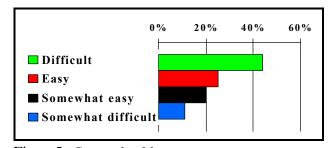


Figure 5: Getting health insurance

• 20% (or 44) said it was somewhat easy and,

• 25% (or 55) said it was easy,

Current coverage:. From the survey, 265 answered the current coverage question. Of these 265 respondents:

- 49% (or 131) have Medicaid card,
- 34% (or 90) have No coverage,
- 12% (or 34) have Private health insurance coverage,
- 8% (or 21) enjoy Medicare coverage,
- 5% (or 15) have other,
- 2% (or 5) CHAMPUS/ CHAMPUS VA

Conclusion: In planning for their future young adults with special health care needs have difficult decisions to make about their independency. When they leave home, they'll have to look for jobs that have benefits with good health care coverage. Otherwise, they will have to spend what they earn to pay their medical costs. 55% of our study population reported some difficulty securing health care coverage. One third of those who responded indicated that they did not have any health insurance to pay for their medical bills. More than 50% are covered by some form of public assistance.

D. Diet and Special Nutrition Need

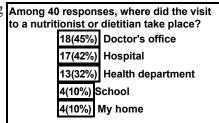
264 responses to questions concerning diet revealed that during the past 12 months:

Among 40 responses, where did the visit to a nutritionist or dietitian take place?

- Only 15% (or 40) had seen a nutritionist or dietitian during the past 12 months,
- 83% (or 219) had not seen anyone during the past 12 months,
- 2% answered "Don't Know."

In response to whether the individual is on any kind of special diet:

• 11% of 266 responses said they are on some kind special diet,



• 10% (or 26) of 260 responses indicated a special drink or food for their diet had been prescribed, but 73% (or 19) of those were using it.

Conclusion: In the 1994 Needs Assessment of CSHCN, 68% indicated ever have seen a nutritionist or dietician. In this survey, we found an even smaller percentage (15%) of young adults with special health care needs had seen a nutritionist or dietitian within the previous year.

E. Access to Support System

For a growing young adult, family and friends play a great role in creating personal vision for the future. In the transition from childhood to adulthood other services such as personal counseling with a specialist might play a pivotal role in planning for the future.

Among 261 responses to whether the young adult had seen a social worker or psychologist:

• 25% (or 64) said they had, (for places where the visit took place see Figure 6)

For social support:

• 28% (or 72) of 255 responses said they have friend with long term health care conditions,

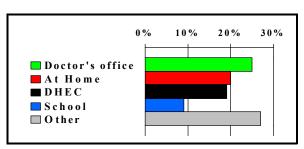


Figure 6: *Places a social worker or a psychologist is accessed*

- 24% (or 61) of 259 responses indicated they are member of an organized group (e.g. Kiwanis Club) or a support group (e.g. Young Adults with Diabetes) or a church group,
- 35% (or 90 of 256) respondents said they do not spent as much time with others as they like,
- For spending their time with, an overwhelming majority indicated preference to spent time with their family members (see Figure 7 for more detail)

Conclusion: There is a clear preference among the young adults participated in this survey over spending time with their family members. One out of every four young adults had seen a social worker or psychologist. The same numbers of

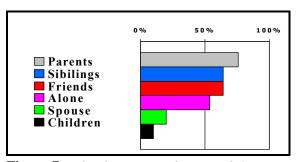


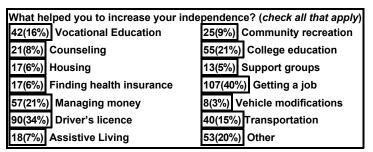
Figure 7: Who do you spend time with?

responses indicated they are member of an organized group. These young adults are not isolated.

F. Level of Independence

Among 267 responses 85% indicated the young adult lives with family; 8% are married, 7% live alone, and 8% have other living arrangements.

- When asked what may help increase their **independence**, among 267 responses:
 - 40% answered getting a job,
 - 34% answered getting a driver's licence,
 - 21% answered managing money,
 - 21% answered college education



- When asked about **total dependence** on others for ordinary activities:
 - 7% of 252 could not walk or move around.
 - 8% of 251 could not move (like from chair to a bench),
 - 6% of 251 could not communicate or talk,
 - 8% of 250 could not write,
 - 9% of 252 could not groom,
 - 10% of 192 could not use special equipment,
 - 12% of 234 could not take medication,
 - 7% of 251 could not tell when healthy or not.

Conclusion: A few responses reported their total dependence on their family members and other care givers. They make up six to twelve percent of the young adults with special health care needs

in the survey. Getting a job, a driver's licence, managing money or college education are among recognized factors to help the young adult's independence.

G. Transitional Services

The first question on transition asked "Before you turned 18 years of age, which one of the following agencies provided you with transitional services (i.e. securing employment, job training, college, etc.)?" A total of 108 (40%) left this question blank and did not make any mark on the response area. We made personal phone calls to determine if the question was vague or weather they actually did not receive any transitional services or a combination of both explanations.

Of 246 responses 14% (or 34) indicated they did not receive any transitional services from any sources:

- 79% (or 195) indicated they had received transitional service from school, mostly for securing employment (59), College (48) and Job training(48),
- 61% (or 150) indicated they had received transitional service from other sources, mostly for independent living (44) securing employment (26), College (25) respondents,
- 46% (or 114) indicated Vocational Rehabilitation Services provided them with transitional service, mostly for securing employment,
- 33% (or 82) indicated DHEC (CRS) provided mostly transition to adult care (55),
- 6% (or 14) indicated that no advocacy organization played a transitional role.

Other demographics of 212 responses with any transitional services:

- 54% Female,
- 59% Black,
- 75% indicated they have seen a doctor with last 12 months,
- 66% indicated they are in need of dental health care needs,
- 26% were refused a health care service

Conclusion:

The majority of the young adults responding indicated they had received some kind of transitional services from a public setting. Only 34 (14%) of 246 respondents did not receive any transitional services. From the 246 who answered the transitional questions, they indicated their school provided most of the transitional services to secure employment, College or Job training. The

Vocational Rehabilitation services provided them with securing job and CRS assisted them with their transition from pediatric care to adult care.

Limitations:

- Children with Special Health Care Needs and their families who had never been served by the CRS program were not included in this approach. These families may come from both sides of the spectrum, and therefore may different unmet needs.
- Most of the historical questions rely on the memory of a person who completed the survey. Furthermore, there are no available external sources to validate the accuracy of responses. Thus, our results may be subject to time elapsed distortion.
- Family satisfaction: Satisfaction with services that these families received was not assessed in this questionnaire.

APPENDIX I

Questionnaire and Reported Results

Results of South Carolina Statewide Needs Assessment of Young Adults with Special Health Care Needs Questionnaire

May 15, 2000 n=267





The Department of Health and Environmental Control
Children Rehabilitative Services
1751 Calhoun Street
Columbia, SC 29201-2606
(803) 898-0742 or 1-800-868-0404

This survey is about young people with special health care needs. Please take a few moments to answer these questions and return the survey to us by placing it into the enclosed envelop which is already stamped and addressed. We will not share your name with anybody else and your responses will be kept private. Your experience and opinions will help us to plan future programs. Thank you for sharing this information.

If you are unable to complete this survey, please check \cup this box 9 and return it to us and explain the reason.

If you have any questions or concerns, please call us at (803) 898-0688 in



Young Adults Needs Assessment (P	₽aqe 19)	

Columbia, or 1-800-868-0404 outside of Columbia area.

Information about you.

Please check (U) only one of the responses which best describes you: 95(36%) Young adult with special health care needs 152(57%) Parent of a young adult with special health care needs 11(4%) Family member of a young adult with special health care needs 0 (0%) Friend of a young adult with special health care needs 9(3%) Other relationship: (please specify Caregiver, House manager, Step father, et	tc.)
If you are completing this survey for a young adult with special health care needs, please answer these questions as they apply to the young adult with special health care needs. There is an explanation of terms provided on the last page.	
About your health.	
n=250 Q1. Do you (a young adult) have any special health care needs? 37 (15%) No 213 (85%) Yes (what:)
n=252 Q2. Are you currently getting the type of medical care that you need? 149 (59%) Yes 103 (41%) No	
n=259 Q3. During the past 12 months, have you seen a doctor for your medical care? 196 (76%) Yes (Go to 3.a) 63 (24%) No (Go to Q4.)	
a. Who provides this medical care to you?(check all that apply) 115 (59%) General Practi/Family Doc 12 (6%) Pediatrician 95 (49%) Specialist 46 (24%) Emergency Room Doctor 4 (2%) Internist 16 (8%) Other	
b. Where do you go to see this medical doctor or health care provider? 65 (33%) Hospital clinic 34 (17%) Emergency Room 17 (9%) Health department 115 (59%) Private office 19 (10%) Other (specify)	
c. Do you consider him /her your primary care doctor? 149 (76%) Yes 43 (22%) No	

n=245 Q4.	During the past 12 months, which of the following situations have been a problem for you? (check all that apply)
n=175 n=218	· · · · · · · · · · · · · · · · · · ·
n=263 Q5. n=189	Currently, do you have any dental health care needs? 181 (69%) Yes (Go to 5.a) 82 (31%) No (Go to Q6.)
n=208	a. Do you need one or more of the following? <i>(check all that apply)</i> 44 (23%) dental braces 165 (87%) regular dental care 24 (13%) oral surgery
	b. Do you need assistance paying for your dental health care needs? 144 (69%) Yes 64 (31%) No
n=262 Q6.	Since you have turned 18 years of age has a doctor or other health care worker refused to provide you with services you felt you needed? 81 (31%)Yes (Go to 6.a) 181 (69%)No (Go to Q7.)
n=81	a. Why were services refused? <i>(check all that apply)</i> 16 (20%) Unpaid bills 26 (32%) Not covered by insurance 10 (12%) Used limit on medicaid 17 (21%) Don't take Medicaid 44 (54%) No money, no Medicaid & no insurance 8 (10%) Don't know 8 (10%) Doctor did not think the service was needed 12 (15%) No money, but have insurance (have to pay "up front") 22 (27%) Other (specify)
n=267 Q7.	Is there any medicine you need for your conditions but cannot get? 64 (24%) Yes (Go to 7.a) 203 (76%) No (Go to Q8.)
n=64	a. What is the reason you cannot get the medicine?(check all that apply) [6 (9%)] Unpaid bills [19 (29%)] Not covered by insurance

	Pharmacy does not carry it. 5 (8%) Don't take Medicaid 48 (75%) No money, no Medicaid & no insurance 21 (33%) have to pay "up front" (12%) Other (specify)
Q8.	What advice would you give to someone with a similar health condition as they move from pediatric to adult health care?
About	your health care coverage.
n=223 Q9. 99(During the past 12 months getting health insurance coverage has been 44%) difficult 25(11%) somewhat difficult 44(20%) somewhat easy 55(25%) easy
n=265 Q10.	At this time, which type of insurance coverage do you have: <i>(check <u>all</u> that apply)</i> 5(2%) CHAMPUS/ CHAMPUS VA coverage 131(49%) Medicaid card 90(34%) None 14(5%) Other: {CRS 4, {Other 10
About n=264	your diet.
Q11.	During the past 12 months, have you seen a nutritionist or dietitian? 40(15%) Yes (Go to 11.a) 219(83%) No (Go to Q.12) 5(2%) Don't Know (Go to Q.12)
	a. Where did the visit take place? 17(42%) Hospital 4(10%) School 18(45%) Doctor's office 4(10%) My home 6(15%) Other (specify)
n=266 Q12.	Are you on any kind of special diet? 233(88%) No 3(1%) Don't Know 30(11%) Yes (explain):
n=260	
Q13.	Has a doctor or a nutritionist prescribed any special food or drink for you? 26(10%)
	Yes (Go to 13.a) 234(90%) No (Go to Q14.)

	13.a	Are you taking that special food or drink? 19(73%) Yes (Go to Q14.) 2(8%) No (Go to 13.b) 5(19%) Missing
	13.b	Why aren't you taking it (explain)?5
About	your S	upport.
n=261		
Q14.		the past 12 months, have you seen a social worker or psychologist? Yes (Go to 14.a) 191(73%) No (Go to Q15.) 6(2%) Don't Know (Go toQ15.)
	14.a	Where did the visit take place? 16(25%) Hospital 6(9%) School 12(19%) Health department 16(25%) Doctor's office 3(20%) My home 17(27%) Other (specify)
n=255 Q15.	Do yoι	u spend as much time with others as you would like?165(65%) Yes 90(35%) No
n=255 Q16.	Do any	of your friends have long term health conditions? 72(28%) Yes 183(72%) No
n=265 Q17.	143(54 ⁹	o you spend time with? <i>(check all that apply)</i> %) Myself 203(76%) My parents 53(20%) My significant other/ spouse %) My friends 171(64%) My brothers & sisters 27(10%) My children
	·	{33 Extended Family, {11 Church
n=259 Q18.	-	u a member of an organized group (e.g. Kiwanis Club) or a support group (e.g. Adults with Diabetes) or a church group? 61(24%) Yes 198(76%) No
<i>About</i> n=267	your le	evel of independence .
Q19. 176(66° <mark>166(62°</mark> 164(61°	%) fix yo %) do y %) mak	u now: (check all that apply) our own meals 30(11%) live with roommates/s 140(52%) manage your own money your own laundry 18(7%) live alone 108(40%) drive a car se your own decisions 228(85%) live with family 68(25%) have a vehicle your own house cleaning 14(5%) Other (please list):

Q20. What helped you to increase your independence? (check all that apply) 42(16%) Vocational Education 25(9%) Community recreation 21(8%) Counseling 55(21%) College education 17(6%) Housing 13(5%) Support groups 17(6%) Finding health insurance 107(40%) Getting a job 57(21%) Managing money 8(3%) Vehicle modifications 90(34%) Driver's licence 40(15%) Transportation 18(7%) Assistive Living 53(20%) Other: (please list) {27 family or Self}

Q21. Do you do the following activities <u>Alone</u>, <u>With help</u> or <u>Total assistance</u>:

	Alone	With help	Total assistance	
Walking or moving around	224	20	17(7%)	n=252
Moving (like from a chair to a bench)	220	14	19(8%)	n=251
Communication and talking	211	27	14(6%)	n=252
Writing	207	23	21(8%)	n=251
Grooming	204	26	23(9%)	n=253
Caring for your daily health needs	183	46	25(10%)	n=254
Using special equipment	137	36	19(10%)	n=192
Taking medication	175	32	28(12%)	n=235
Knowing when you are healthy or getting sick	188	46	18(7%)	n=252
Other:				n=17

The next set of questions are about transitional services.

Q22. Before you turned 18 years of age, which one of the following agencies provided you with transitional services (i.e. securing employment, job training, college, etc.)? (check all that apply)

11 37					
	DHEC (CRS)	School	Vocational Rehab	Advocacy Organization	Other
Securing employment	10	59	56	3	25
College	3	53	13	1	26
Job training	5	48	27	6	21
From Pediatric care to Adult care	55	14	13	7	37
Independent living	9	21	5	3	44
	82	195	114	14	150

About	your	educa	tion.
-------	------	-------	-------

n=260 Q23. Are you in school? 86(33%) Yes (Go to 23.a) 174(67%) No (Go to 24) What was the last grade or degree you completed: 23.a (172) High school ____ (51) College ____ Years (18) Other:_ (What grade) (What year) n=245 Q24. When did you start making plans for what you would do after high school? During 63(26%) 10th grade, 37(15%) 11th grade, 44(18%) 12th grade {~59%} 49(20%) don't know 20(8%) Other 32(13%) Never

Q25. Who was helpful to you in making your after high school plans (check all that apply):

	Very Helpful	Helpful	Not Helpful	
Myself	142	35	16(8%)	n=193
My Parents	140	55	9(4%)	n=203
My brothers and sisters	56	48	33(24%)	n=137
High School program	57	48	32(23%)	n=95
Health Professional	15	27	54(57%)	n=111
Vocational Rehabilitation	35	25	51(46%)	n=100
People in the community (Scouts, clubs, neighbors)	23	37	40(40%)	n=28
Others:				

More	about	you.
------	-------	------

Q26.	First Name MI	Last Name	Age {Average=20}	126(48%) Male	136(52%) Female
------	---------------	-----------	------------------	---------------	-----------------

Q27. Please tell us your race or ethnic background? 155(63%) Black, 90(37%) White, 1 Amr Ind

				? (<i>check all that apply</i>) t-time job 71(27%) Family 29(11%) Other
	If working:	28.a	Where do you work	.?
		28.b	What is your job?	
n=109				
'		28.c	Do you need specia 96(88%)	al equipment to do this job? 13(12%) Yes (<i>What</i>)
		28.d	Do you need specia	al preparation to get ready to do this job? 8(7%) Yes (<i>What</i>)
Q29.	How many pe	ople liv	ve in your home?	Average=3.7 , Median=3
Q30.	Please estima	ate you	r annual income:	Average=\$7,679.29 Median=\$6,000.00
Q31.	Are you marr	ied?	234(92%) No	21(8%) Yes
Q32.	Your telephor	ne num) a code)
Q33.		family	that can help us pla	nything else about yourself, your health, your n to better meet the needs of young adults with

Thank you for helping us by filling out this survey. attached envelope and mail it to us.	Please fold this document and place it in the
Young Adults Needs Asses	sment (Page 27)

Explanation of Terms

For this questionnaire, the terms used are defined as follows:

Adult Care - Health/medical care usually provided to persons over 18 years of age.

General Practitioner - A medical professional whose practice is not limited to any specific

branch of medicine.

Health Care Provider - A professional who provides health care who may or may not be a doctor

or nurse.

Internist - A doctor specializing in internal medicine.

Medical Specialist - A doctor who sees a patient in need of special medical care. This doctor has

advanced knowledge and skills to treat patients who have special medical conditions (i.e. Diabetes, Sickle cell). The patient's primary care physician usually refers patients to a medical specialist when she/he is unable to provide

specialized medical care.

Nutritionist or Dietitian - A professional who has special knowledge and skills concerning

our body's requirement for food, liquid, and other diet needs for proper

health and development.

Pediatric Care - Health/medical care usually provided to persons under 18 year of age.

Pediatrician - A doctor specializing in the development, care, and diseases of children.

Primary Care Physician - A doctor who is familiar with all her/his patient's medical conditions and

is the first doctor the patient goes to see when she/he has a medical

problem.

Psychologist - A professional who has special knowledge and skills about our mind and human

and animal behavior.

Social Worker - A professional who has special knowledge and skills to provide services and

activities designed to improve social conditions of people.

Special Health Care Needs - A medical condition or illness that lasts a long time. It may last a

lifetime.

SSI- Supplemental Security Insurance - A method of payment provided to people with

disabilities who are unable to pay for health/medical

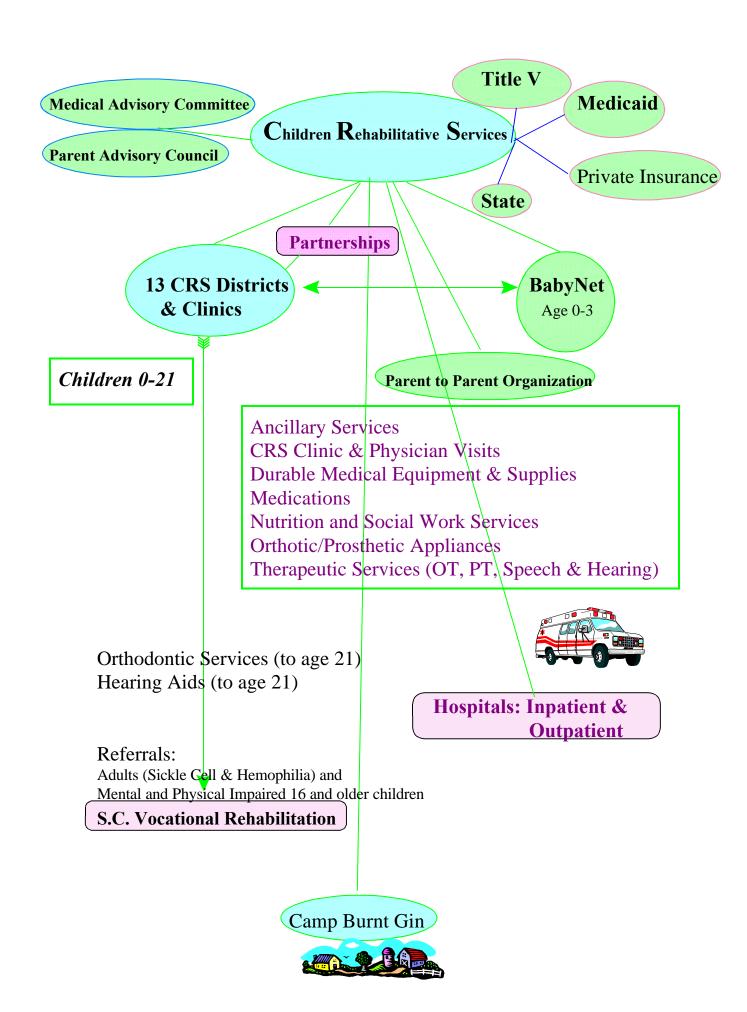
care and medicine.

APPENDIX II

Attached Letter to the Questionnaire

July 15, 1999
[Contact name] [Contact address]
Dear parent/care giver,
One of our goals in the Children Rehabilitative Services (CRS) of Department of Health and Environmental Control is to better serve our state's children with special health care needs. We are contacting you because [child's name] has, in the past, received services through CRS. We need your help in understanding whether [child's name]'s health care needs are being met at the present time.
Enclosed, is a set of questions that should take only a short time to complete. Your answers to these questions will help us know what young adults' needs are today. We would appreciate it, if you could complete this survey, insert it in an envelop and send it back to us as soon as you can. The enclosed envelop is already stamped and addressed for your continence. As a "thank you" we will send you a \$5 gift certificate if we receive your completed survey by August 20, 1999.
For more information and if you have any questions, please call Mr. Heidari at 898-0688 in Columbia, or 1-800-868-0404.
Sincerely,
Linda D. Price Director, CRS
Enclosures

APPENDIX IIISchematic Display of CRS Services



Summary of reports from Needs Assessment Committees

MCH Population Focus: Reproductive-Age Women, Ages 15-44

Committee Chair: Kahlil Demonbreun

Co-Chair: Herman Core

Members:

Andreina Angle

Brenda Cresswell

Kristen Helms

Julie Lumpkin

David Thomas

Lavelle Thornton

Crosscutting Issues: Those that underlie all priority health need categories.

 The need to continue and further enhance the use of indigenous/lay community workers to convey messages to clients.

- 2. The need for more cultural diversity among public health (health service) providers.
- 3. The need to communicate a reality-based message for early prenatal care that is relevant to the target population.
- 4. The need to identify a "Next Step" to follow the extensive staff training on issues around customer service and cultural competency, to integrate and apply areas of training, and to hold staff accountable for the quality of care and services that they provide.
- 5. The need to incorporate more ways to solicitor involve clients served in the public health sector in health planning and program development.
- 6. The need for improving skills of staff in taking a good health history. Steps include:
 - 1. evaluating current knowledge, skills, and abilities of staff;
 - 2. developing individualized plans to address staff deficiencies;
 - 3. holding staff professionally accountable for performance and for maximizing the likelihood of positive health outcomes
- 7. The need to evaluate staff's ability and willingness to provide services in a non-judgmental way.
- 8. The need to implement and hold SC-DHEC accountable for providing services and health promoting literature for increasingly diverse populations.

Priority Health Needs for Women of Reproductive Age

1. Pregnancy

- A. Problems associated with infertility: Public Health Should:
- 4. Assure access to continued screening and treatment of women at risk for chlamydia and gonorrhea. (Population-Based)
- 5. Educate public, private, and third party sectors about the incidence, prevalence, and public health consequences of chlamydia and gonorrhea. (Infrastructure Building)
- 6. Develop and implement policies to broaden the scope of screening to include all women at risk.

 (Infrastructure Building)
- B. Problems associated with unintended pregnancy and repeat abortion: Public Health Should:
- 7. Assist public, private, community and political leaders in developing and maintaining an attitude that unintended pregnancy is a health care issue as opposed to one of sexuality and morality.

 (Infrastructure Building)
- Access statewide access to family planning service methods for all reproductive age women. (Direct Care Services)
- 9. Increase partnering with community, private, and other public health agencies and assist these sources with providing family planning services. (Enabling Services)
- 10. Increase partnerships with private, public, and community organizations to educate pre-teens on issues of reproductive health and sexuality. (Infrastructure Building)
- 11. Partner with universities to conduct and/or support research efforts aimed at providing evidence-based recommendations to third party providers. (Infrastructure Building)
- C. Problems associated with low birth weight: Public Health Should:
- 12. Conduct efforts aimed at increasing awareness of the adverse health consequences associated with use of tobacco, illegal drugs, and alcohol. (Infrastructure Building)
- 13. Develop and implement policies aimed at assuring that all women of reproductive age receive an annual exam to include preconceptional counseling. (Infrastructure Building)
- 14. Develop partnerships with private sector providers to assure that all women of reproductive age have a medical home. (Enabling Services)
- 15. Develop and implement programs that assure all pregnant women will receive appropriate prenatal care. (Infrastructure Building)
- 16. Assure all women of reproductive age access to adequate nutritional resources and services.

 (Infrastructure Building)

2. Access to Health Care

- A. Limited access impacts quality of life: Public Health Should:
- 17. Develop and implement programs that assure all women of reproductive age have access to primary health care services. (Infrastructure Building Services)
- 18. Provide ancillary primary care services for women without medical homes. (Direct Health Care Services)
- 19. Develop and implement policies to broaden the baseline scope of services for women of reproductive ages. (Infrastructure Building)

3. Chronic Disease

- A. Chronic disease impacts quality of life: Public Health Should:
- 20. Collaborate with public and private community organizations to assure that all women with chronic health conditions (e.g., HIV/AIDS, diabetes) have a health care home or have access to adequate health care. (Enabling Services)
- 21. Provide ancillary primary care services for those women without medical homes. (Direct Health Care)
- 22. Develop and implement policies to broaden the scope of services for women with chronic illnesses.

 (Infrastructure Building)
- 23. Develop partnerships with universities, pharmaceutical, and private entities to increase research efforts to address and prevent chronic illness. (Infrastructure Building)

MCH Population Focus: Pregnant Women and Infants

Committee Chair: Burnese Walker-Dix

Co-Chair: Patsy Myers

Members:

Elin Holgren

Luanne Miles

Marge Heim

Otis Outing

Sarah Fellows

Jan Cauthen

Madie Robinson

Crosscutting Issues: Those that underlie all priority health need categories.

- 1. Access to prenatal care
- 2. Resources to address behavioral, psychosocial, and educational issues
- 3. Environmental issues
- 4. Nutritional issues
- 5. Data collection and monitoring capacity
- 6. Access to safe, affordable child care

Priority Health Needs for Pregnant Women and Infants

- 1. Access to prenatal care. In keeping with its core functions, Public Heath should assure access to quality prenatal care that is customer-focused, culturally sensitive, readily available, and comprehensive. (Enabling)
- Access to risk-appropriate care for pregnant women with special needs. In keeping with its assurance function, Public Health should monitor high risk pregnancies and their outcomes to make sure that women have access to risk-appropriate health care. (Enabling and Infrastructure)
- 3. Increase the percentage of infants and new mothers who receive newborn home visits. Public Health should assure that all infants receive a newborn home visit to identify an appropriate medical home for the infant and o establish an early link to a reliable and comprehensive system of health care as well as to valuable community-based services. (Population-Based)
- 4. Need for adequate health insurance coverage. Public Health should continue to assure health care coverage that includes enabling services to promote and enhance optimal health for all infants. (Enabling Services)
- Access to preconception and interconception family planning health care services. Public Health should assure
 access to pre-conceptional and inter-conceptional care including nutritional and risk assessments, medical

- and psychosocial interventions and health promotion to reduce the risk of adverse pregnancy outcomes. (Enabling Services)
- 6. Need for preventive and therapeutic interventions. Public Health should assure that the behavioral, psychosocial, educational, and environmental needs of pregnant women are addressed through comprehensive health promotion, preventive, and therapeutic interventions. (Direct Care and Enabling Services)
- 7. Need for parenting education. Public Health should assure efforts to educate and support parents about developmental milestones in infancy and childhood and their relationship to health and child development. I should promote, through education, an awareness of the importance of raising an infant in a nurturing, safe environment, and should increase parental awareness of factors that enhance optimal infant development (e.g., breastfeeding, car safety, infant stimulation, etc.). (Enabling Services)
- 8. Need for accurate nutrition information and for nutritious food s. Public Health should assure the promotion of optimal nutritional status of pregnant and breastfeeding women and infants by disseminating accurate nutrition informationand assuring access to nutritious foods. (Direct Care Services)
- 9. Need for accurate, quality data collection. Public Health needs to promote the development of a comprehensive, consistent, and high quality data collection that allows analysis and monitoring of current as well as evolving systems of perinatal health care. (Infrastructure Development)
- 10. Need for understandable and timely information. Public Health needs to assure that data are collected, analyzed, and disseminated in a timely way and in a format that supports health planning and stimulates thought about health policy. (Infrastructure Development)
- 11. Need for quality, affordable child care. With over 60% of mothers in the workforce, Public Health should assure the availability of quality, affordable child care within the community by (a) supporting efforts to establish a monitoring system for child care providers, and (b) supporting efforts to train child care providers about child development, symptoms of illness, safety, nutrition, and general health. (Population-Based)

MCH Population Focus: Children Ages 1 - 9 Years

Committee Chair: Angie Olawski

Co-Chair: Members:

Crosscutting Issues: Those that underlie all priority health need categories.

1. Poverty

2. Issues associated with cultural diversity

3. The knowledge, skills, and abilities of parents, care-givers, and health care providers.

Priority Health Needs for Children Ages 1 - 9

1. Access to primary and preventive care: medical home, dental care, mental health (parent, child, and care giver), health insurance, manpower, transportation.

- Recommendation 1: Public Health should support collaboration among public, private, and community partners to launch a broad-based public awareness campaign to improving children's health outcomes. (Population Based Services)
- Recommendation 2: Public Health should assure access to coordinated and comprehensive, and
 preventive, health promoting, therapeutic, and rehabilitative medical, mental, and dental care, and
 transportation for these services. (Enabling Services)
- Recommendation 3: Public Health should ensure the enrollment of insured children into the State's
 Child Health Insurance Program, Partners for Healthy Children, and promote expansion of the
 program to children in all low income families. Enabling Services and (Infrastructure Building)
- Recommendation 4: Partnerships between providers of care should exist in every county to assure medical homes and the coordination of services. The Public Health partner will promote adherence to established standards of care. (Infrastructure Building Services)
- 2. Injury: intentional and unintentional
 - Recommendation 1: Public Health should encourage efforts to emphasize the prevention of
 unintentional injuries, especially those related to motor vehicles, fires, poisoning, falls, drowning,
 suffocation, and playgrounds through the promotion of activities such as fire safety education,
 child safety seats, child-proofing homes, etc. (Population Based)
 - Recommendation 2: Injury prevention informational education should be provided to parents of children in conjunction with other services already being provided in the Public Health system.

 (Enabling Services)

- Recommendation 3: Public Health should employ risk-assessment method to identify and link children at risk of intentional injury to appropriate intervention services. (Infrastructure Building and Enabling Services)
- Recommendation 4: Expand, where feasible, proven parent education, support, and counseling programs to prevent intentional injuries. (Population-Based Services)
- 3. Behavioral risks: nutrition, physical activity, smoking, substance abuse
 - Recommendation 1: Public Health should promote awareness through public information efforts of the adverse effects of smoking, substance abuse, poor nutrition, and lack of physical activity.
 (Population Based Services)
 - Recommendation 2: All Public Health services to children and families (whether community-focused or individually-focused) should incorporate education that includes proper nutrition, the importance of physical activity, and the adverse effects of smoking, substance abuse, and other risk-taking behavior. (Population Based Services)
 - Recommendation 3: Children and families should be assessed for behavioral risk factors and referred to supportive services. (Enabling Services)
- 4. School health: readiness, health care, health education
 - Recommendation 1: Public Health should partnerships between schools in every county to promote integrated school health programs. (Infrastructure Building Services)
- 5. Vaccine-preventable diseases
 - Recommendation 1: Public Health should assure that all children receive recommended immunizations by promoting public awareness and family-friendly access to vaccinations.

 (Population Based Services)
- 6. Environmental exposures: lead, second-hand smoke
 - Recommendation 1: Public Health should assure that systems are in place to test for lead in the
 environment, screen children who are at greatest risk, and treat children who have lead poisoning.
 (Population-Based Services)
 - Recommendation 2: Information should be made available to the public and to clients about the consequences of exposure to second-hand tobacco smoke for children. (Population Based Services)
- 7. Chronic illness: ADHD, asthma, etc.
 - Recommendation 1: Public Health should assess the availability of services for children with chronic illness and work to improve access to these services. (Infrastructure Building Services)
 - Recommendation 2: Children with chronic illnesses should be referred to supportive services.

 (Enabling Services)

MCH Population Focus: Adolescents and Young Adults Ages 10 - 21

Committee Chair: Sandra Jeter

Co-Chair: Herman Core

Members:

Crosscutting Issues: Those that underlie all priority health need categories.

Social determinants of health such as economics, poverty, education, literacy, and cultural values directly impact access to and utilization of resources. In order to address and have an impact on the multiple needs of our adolescent population, it is evident that we must form partnerships with all youth-serving agencies. Representative examples include the Department of Alcohol and Other Drug Abuse Services, the South Carolina Department of Education, the Department of Mental Health, the Department of Juvenile Justice, the Department of Disabilities and Special Needs, and the Department of Public Safety.

Priority Health Needs for Adolescents and Young Adults

1. Reduce intentional and unintentional injuries (homicide, suicide, motor vehicle and other injuries)

Population Based Services

 Recommendation: Promote enforcement of existing laws and regulations on the use, purchase and sale of alcohol, drugs, and tobacco; promote education related to firearm safety, seat belt use, and safety precautions in sports.

- Promote water safety education as well as regulations around operation of water crafts
- Screen all adolescents and young adults for the risk of suicide
- Development and implement injury prevention plans in districts in collaboration with community coalitions
- 2. All children and young adults ages 10 21 need a medical home
- Recruit medical, dental, and mental health providers, including services for STD/HIV, obesity, and family planning for under-served areas. Direct Care
- Enroll more adolescents in SCHIP. Enabling Services
- Develop and design public awareness campaigns aimed at the reduction of stigma associated with the use of mental health services. Population Based Services
- 3. Reduce drug, alcohol, and tobacco use. Infrastructure and Population Based Services
- 4. Reduce teen pregnancy. Direct Health Care Services
- 5. Adolescents need to eat a nutritionally balanced diet. Infrastructure-Building Services
- 6. Adolescents need to be more physically active. Infrastructure-Building Services

MCH Population Focus: Children with Special Health Care Needs

Committee Chair: Linda Price

Co-Chair: Donna Rickert

Members:

Crosscutting Issues: Those that underlie all priority health need categories.

Recommendations:

 Facilitate a multi-agency task force to address a coordinated system of care for CSHCN (to include, but not be limited to, medical, psychosocial, education, and care-giver supports) through a central point of entry and coordination of care. Infrastructure Building

- 2. Examine the system of respite care and develop recommendations to enhance the service. Enabling Services
- 3. Examine financial access for CSHCN to include, but not be limited to, provider reimbursement rates, insurance coverage, dental care, ancillary services (e.g., assistive therapies, personal care attendants, and durable medical equipment); medications, waivered services (e.g., skilled nursing), mental health, long-term care in compliance with federal mandates, respite care, and housing. Population Based
- 4. Formalize a plan to assure that all providers of services to CSHCN are appropriately trained to provide coordinated, family-centered, culturally competent, and community-based care. Infrastructure Building
- Facilitate the education and training of children with special health care needs and their families to include, but not be limited to activities for daily living, post-secondary education, vocational rehabilitation, self-advocacy, and independence and self-management. Enabling and Population Based
- 6. Develop a transitional services system of care to include, but not be limited to medical, psychosocial, and educational services. Infrastructure Building
- 7. Evaluate the existing transportation systems for children with special health care needs and their families and develop recommendations to improve access to transportational services. Enabling Services